

Successful Transition Planning for Students Who Have Severe Disabilities:
Parents' Perspectives

by

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Table of Contents

Chapter

1.	INTRODUCTION	
	Purpose for Transition Planning.....	1
	IDEA Requirements.....	7
	Family Involvement	9
	Assessing Effectiveness	10
	Purpose for this Study.....	13
	Methodology	15
	Research Questions.....	16
	Definition of Terms.....	18
2.	REVIEW OF THE LITERATURE	
	Historical Perspectives.....	20
	Evolution of Transition Planning.....	22
	Outcomes of Transition Planning	25
	Developing Effective Transition Plans.....	30
	Indicators of Successful Transition Planning.....	41
	Theoretical Basis for This Study.....	44
	The Role of Qualitative Methodology	51

3.	METHODOLOGY	
	Qualitative Methodology in Special Education Research	54
	Theoretical Perspective for This Study.....	57
	Site Selection and Participants.....	59
	Instrumentation	62
	Data Analysis	65
4.	ANALYSIS OF THE DATA	
	Cases.....	77
	Cross Case Analysis	84
	Interpretations	98
5.	SUMMARY,CONCLUSIONS, DISCUSSION, RECOMMENDATIONS	
	Limitations.....	100
	Conclusions	101
	Recommendations	102
	Final Thoughts	105
	References	108
	Appendices	
	Appendix A Interview Protocol	117
	Appendix B Informed Consent	120
	Appendix C Transcription Instructions	122
	Appendix D IRB Approval	124

Chapter 1

Introduction

High school graduation marks a turning point in the lives of young people and symbolizes the transition from adolescence to adulthood. When students with severe disabilities graduate from high school, they leave the security and familiarities of the special education services provided by the school and enter the world of adult services. In order to ensure this transition is successful, the special education professionals working with these students must plan for this transition. Facilitating such a plan is a complex process; there is no such thing as a one-size-fits-all transition plan for students with severe disabilities. Instead, special education professionals must consider a myriad of factors, especially the desires and perspectives of the students' parents or guardians.

Purpose for Transition Planning

A successful transition from high school to the adult world doesn't just happen. A transition plan designed to access supports and services necessary for establishing the kind of adult life desired by the individual and his or her family, is crucial. Anticipation of high school completion and plans for employment and independent living guide transition planning for students who have severe disabilities. According to Levitt, Silver, and Santos (2008) high school graduation is defined as follows:

A marker event that heralds the adolescent's entry into young adult life.

Developmentally, the transition to adulthood is a pivotal period for intergenerational relations, as both the adolescent and the parent must

reconfigure the relational asymmetry characterizing the child's pre-adult period (p.53).

High school graduation most often is a rite of passage and a time for celebration for students and their families. For students who have severe disabilities, however, and their families, high school graduation may signal a time marked by uncertainty in employment opportunities, limited residential options and heightened social isolation. The transition from school to adult life may be a time of stress, upheaval within the family structure, and uncertainty about future residential and vocational options (Flexor, Baer, Luft, & Simmons, 2009; Kim & Turnbull, 2004, Neece, Kraemer, & Blacher, 2009; McDonnell & Hardman, 2010).

Flexor et al. (2009) further illustrated the complexity of planning for the completion of formal public education and entry into the realm of adult services for students who have severe disabilities with the following:

For students with disabilities, transition planning is particularly important because, in addition to the normal upheaval in the transition to adulthood, students with disabilities exchange the security of a single contact point- special education- for the complexity of multiple systems serving adults with disabilities (p. 9).

Given the challenges families face as they engage in transition planning for their son or daughter who has a severe disability, it is essential that families locate and access appropriate supports both during and following the transition period. According to Chambers, Hughes and Carter (2004), the development of appropriate supports during this period is critical for achieving identified

outcomes. Students who have severe disabilities are often not afforded opportunities for community living and employment available to their peers who are not disabled and decisions about postsecondary education and/or employment can be especially complex for students who have severe disabilities (Kochhar-Bryant, Shaw, & Izzo, 2009; McDonnell & Hardman, 2010).

McDonnell and Hardman (2010) asserted, "Transition, therefore, must be viewed as a flexible, comprehensive, and coordinated planning process for the individual student, offering options and choices that are aimed at well-defined postsecondary goals" (p. 1). Neece et al. (2009) offered their support as follows:

The transition from adolescence to young adulthood is a critical life stage for all individuals. The period brings about changes that can drastically affect the daily lives of young people and their families. As a result, this transition period may be an especially stressful time. Typically developing high school graduates usually go off to college or enter the workforce. For students with severe intellectual disabilities, however, post school options are often much more limited (p. 31)

The transition to adult life brings with it both opportunities and risks. Changes experienced during this period by both individuals and their families challenge the K-12 educational system as well as the system of adult services. Individuals may seek increased independence while facing new risks. Blacher (2001) stated, "Thus, this period is marked by growth and change but also by increased uncertainties and challenges, and it is important to better understand

the experience of persons and families going through this transitional period” (p. 174).

Students with severe disabilities (including those who have an intellectual disability, autism spectrum disorder, traumatic brain injury, and multiple disabilities) are most likely to need on-going, individualized supports in order to participate in inclusive communities (Neubert & Moon, 2006; Stuart & Smith, 2002). The cognitive and communication limitations of adolescents who have severe disabilities make our understanding of their experiences dependent upon the perspectives and contributions of their family. Parental expectations of future residential or employment opportunities influence the transition planning process (Blacher, 2001, Kraemer & Blacher, 2001, Neece et al. (2009).

Transition from high school to adult life is a developmental process that encompasses major physiological, social, and emotional life changes and adjustments associated with an individual's moving from childhood through adolescence into adulthood. Transition brings with it a change in status from behaving primarily as a student to assuming adult roles in the community. These roles include employment, participating in postsecondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships (Neece et al., 2009).

For students who have severe disabilities, transition planning involves collaboration among multiple stakeholders (the student, parents or guardians, education professionals, adult service providers) and is crucial for both the future well-being of the adolescent and his or her family. One of the most significant

challenges faced as students who have severe disabilities transition to adulthood is the change from a system of entitlement (special education) to a system of eligibility (adult services) (Hughes, 2009, Neece et al. 2009, Neubert, Moon & Grigal, 2002).

McDonnell and Hardman (2010) explored the ramifications of the gap between mandated transition planning practices and the reality of transition as experienced by students who have disabilities and their families as follows:

Although two decades have passed since Congress mandated that transition planning is included in federal law and though new advances in instructional technology have taken place, access to meaningful transition programs is at best “inconsistent” within schools. As such, the intended outcomes of comprehensive transition planning and services for all students with disabilities have yet to be fully realized. However, the critical goal of improving the quality of adult life for students with disabilities remains as important today as when the federal government mandate was initially passed by Congress in 1990 (pp. 3-4).

To further illustrate the problems experienced by students who have severe disabilities as they complete secondary education, Brown, Shiraga, and Kessler (2006) stated the following:

Post-school outcomes realized by the vast majority (of severely disabled individuals) are tragically unacceptable and wasteful of hopes, dreams, lives, and increasingly scarce tax dollars. Far too many exit school and are unnecessarily confined to segregated enclaves, workshops, and activity centers or stay home all day with family members and/or others who are paid to be with them. We must and can do something to change this most unfortunate state of affairs. (p. 93)

Research conducted by Getzel and deFur (1997) supported the assertion that students who have disabilities often struggle after their high school education is terminated with the following statements:

After completing high school, students who have disabilities often find themselves in low paying, unfulfilling jobs and unsatisfactory living situations. Students with severe disabilities face challenges in accessing employment, postsecondary education, living arrangements, and social/recreational activities. Investigations of the post-school outcomes for students with severe disabilities identify chronic unemployment, dependence on family members and service providers, and isolation from the regular daily activities of the community as problems often faced by students and their families (p. 39).

Transition planning is critical for ensuring positive post school outcomes for students who have disabilities. Successful transition planning is the key to the beginning of a successful adult experience in a new employment or residential setting. What comprises successful transition planning, therefore, is

crucial in assisting students who have severe disabilities and their families in negotiating the transition period (Bakken & Obiakor, 2008). Legislatively, The Individuals with Disabilities Education Act (IDEA) mandates transition planning. Legislative mandates, however, do not ensure effective practice.

IDEA Requirements for Transition Planning

IDEA 2004 defined transition services as follows:

A coordinated set of activities for a child with a disability that is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's move from school to post-school activities including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; is based upon the individual child's needs, taking into account the child's strengths, preferences, and interests; and includes instruction, related services, community experiences, the development of employment and other post-school adult living skills, and, when appropriate, acquisition of daily living skills and functional vocational evaluation (Retrieved from <http://idea.ed.gov/>).

Two revisions to IDEA 2004 are relevant to this study. First, IDEA 2004 emphasized accountability in the educational system for improving transition outcomes for youths. Second, IDEA 2004 revised language regarding interagency responsibility for providing transition services and increased the

responsibility of the Individualized Education Program (IEP) process for ensuring that services provided by participating agencies are provided as outlined in the IEP. IDEA 2004 also revised IEP requirements for secondary transition planning. The IEP process facilitates individualized planning during the transition years (ages 14-21). IDEA 1997 moved the date of initiation of transition services from age 16 to age 14 (or younger, if determined appropriate by the IEP team), to be updated annually. IDEA 2004 shifted the mandated age at which transition services are initiated from age 14 back to age 16, or younger if determined appropriate by the IEP team (Kochhar-Bryant et al., 2009).

The IEP must include a youth's present level of educational performance, his or her transition service needs, and measurable annual goals. IEP teams must utilize transition assessments to determine services appropriate for the child's needs in the areas of training, education, employment and independent living (if appropriate). Additionally, the IEP must include a course of study leading to the attainment of the IEP goals. The IEP must also include any interagency responsibilities, accommodations or modifications, and a statement of the special education and related services required for the student to be involved and progress in the general curriculum (Kochhar-Bryant et al., 2009).

The intent of transition planning as mandated in IDEA 2004 was the creation of opportunities for youth with disabilities that would result in positive adult life outcomes. For students who have severe disabilities, transition planning involves engaging in assessments for interests, preferences, and needs, building self-awareness, self-identity, self-esteem, and self-determination

skills. Acquiring the skills and experience necessary for utilizing the community for supports in socializing and developing long-term relationships, as well as engaging in activities both at school and in the community, are essential in the transition planning process (Bakken & Obiakor, 2008, Kochhar-Bryant et al., 2009).

Family Involvement in Transition Planning

Throughout the period of transition from adolescence to adulthood, families remain key players in the lives of individuals who have severe disabilities. The family often plays a critical role in influencing the quality of life for a person who has a severe disability and parents and families are affected by the process of transition from secondary education to adult services. Families, therefore, ought to be actively involved in the process of planning for transition-related changes (Gallivan-Fenlon, 1994; Kim & Turnbull, 2004; Kraemer, McIntyre, & Blacher, 2003; Morningstar, Turnbull, & Turnbull, 1996; Seltzer & Kraus, 2001). According to Ankeny, Wilkins, and Spain (2009), "Families of youth with disabilities face additional sources of stress during the transition concerning their children's social-sexual adjustment, vocational options and career choices, guardianship and advocacy issues, financial security, and needs for recreation and leisure" (p. 28).

Ankeny et al. (2009) continued to explain that parental involvement in the transition of youth who have disabilities is vital for the successful move from adolescence to adulthood. The authors argued that families often piece together support for their adolescent children and juggle multiple responsibilities as they engage in planning for transition. Ankeny et al. suggested, "The wide array of

services available for students with disabilities can involve multiple systems, including education, health, recreation, and vocational rehabilitation, all of which may have distinct eligibility criteria and complex qualification rules” (p. 30).

Ankeny et al. further argued for the necessity of family involvement in planning for transition with the following information:

Transition is an ongoing process of planning, implementing, evaluating, and balancing the details of parents’ lives with the details of their children’s lives to achieve an integrated quality of life for the entire family. Parents are the consistent thread in their children’s lives, and the responsibility for obtaining and following through with adult services for their children typically falls on them (p. 28).

Assessing Effectiveness

To place the questions investigated in this study in the context of a broader perspective, I will first discuss current efforts to determine the effectiveness of transition services delivered to students who have disabilities. The United States Department of Education has twice provided support for longitudinal studies designed to determine the effectiveness of transition programs and services. The first of these studies, The National Longitudinal Transition Study 1 (NLTS1), took place between 1987 and 1991. A follow up study, The National Longitudinal Transition Study 2 (NLTS2), was undertaken in 2001. The NLTS2 documented “the experiences of a national sample of students who were 13 to 16 years of age in 2000 as they move from secondary school into adult roles” (Retrieved from <http://www.nlts2.org/>).

The NLTS2 study included representation of youth in each of 12 federal

special education disability categories. Data were collected in five waves over a nine-year period and included information from parents, youth, school staff, and school records. The NLTS2 comprised a primary source of information on academic achievement, school completion, and postsecondary education and employment. This study focused “on a wide range of important topics such as high school coursework, extracurricular activities, academic performance, postsecondary education and training, employment, independent living, and community participation” (Retrieved August 16, 2011 from <http://www.nlts2.org/>).

Published reports from NLTS2 data detailed the results of the study; one of these is particularly relevant to my study. Wagner, Newman, Cameto, Levine, and Garza (2006) explained that youth who have an intellectual disability or multiple disabilities are among the least likely to be out of school at the typical graduation age of 17 or 18. Even among high school completers, students who have an intellectual disability or multiple disabilities are the least likely to have graduated with a regular diploma. As mentioned by Wagner et al., in two areas associated with post high school success, work and preparation for work or school, adults who have an intellectual disability or multiple disabilities had the lowest reported rate of engagement in work or school of all disability categories.

High school graduates who have disabilities, not just severe disabilities, may struggle to establish themselves in the adult world. Kochhar-Bryant et al. (2009), in discussing the conditions that necessitated the transition revisions in IDEA 2004, stated that “research has documented continuing gaps between young people with disabilities and their nondisabled peers with regard to

education, transition, economic, and independent living outcomes” (p. 3). The authors contended that students who have disabilities continued to fare less well than their nondisabled peers upon completion of high school. Kochhar-Bryant et al. (2009) reported that 22 % of Americans with disabilities fail to complete high school, compared to 9 % of those without disabilities. Compared with their nondisabled peers, students who have disabilities are more likely to be unemployed, live with parents and be socially isolated. Only 28.4 % of Americans with disabilities have access to the Internet at home or work, compared to 56.7 % of those without disabilities. Almost 60 % of Americans with disabilities have never used a personal computer compared to 25 % of Americans without disabilities as indicated by Kochhar-Bryant et al. These statistics may provide some insight into the status of all students who have disabilities in their first several years after high school completion. The post-school status of students who have severe disabilities, unfortunately, remains difficult to assess. Determining if a student who has a severe disability has made a satisfactory transition to adult life may not fully be determined by merely examining the student’s employment or residential status: two areas typically used as measures of high school’s preparation for life. These success measures may indicate post high school attainment of success for students who have relatively mild disabilities; not necessarily so for students who have severe disabilities.

In contrast, a second approach taken in an effort to determine the effectiveness of transition planning for students who have severe disabilities

focuses on assessing subjective, personally valued outcomes related to perceived quality of life. This approach is the focus of this study and will later be discussed in depth. The goal of transition planning for students who have severe disabilities, a timely and successful adjustment from high school special education services to adult services, remains elusive for many. As Kochhar-Bryant et al. (2009) stated:

Studies of transition plans for students show that they do not reflect the requirements of IDEA 1997 or 2004. An increasing number of youths apply for Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) each year, despite significant federal, state and local investment in special education. About 60,000 between the ages of 18 and 24 come on the rolls annually and less than 1 percent ever leave (pp. 3-4).

As Johnson, Stodden, Emanuel, Lueking, and Mack (2002) reminded the field of special education, “Progress in creating comprehensive and responsive secondary education and transition services has, however, been slow and inconsistent across states and school districts nationwide” (p. 520). The authors added that educators have not yet fully incorporated research on effective secondary transition models and services into their practice.

Purpose for this Study

The purpose for this investigation was two-fold. First, I undertook the study with the goal of contributing to a deeper understanding of the experience of transition for students who have severe disabilities and their families. Second,

based on this knowledge, I hoped to provide guidance for educators who are engaged in transition planning with students who have severe disabilities. The purpose for this study was informed by Cobb and Alwell (2007), who contended that despite our empirical and theoretical knowledge, "It seems our greatest need is in applying what we know - informing and supporting practitioners and families in a uniform fashion - so that implementation of effective transition practices for youth with disabilities might become more commonplace" (p. 41).

This study investigated the experiences of three families as they planned for transition from high school to adult life. For students who have severe disabilities, the involvement of a parent or guardian is critical in the development of a plan for successfully accomplishing the transition to adult services. As Levitt et al. (2007) reported, a youngster's relationship with his/her parents or guardian is critical to the adjustments accompanying transition to young adult life.

Transitioning students who have severe disabilities from secondary education to post-secondary services involves coordinated planning on the part of multiple service systems (Blacher, 2001; Neece et al., 2009). Assessing the success or failure of transition planning for students who have severe disabilities involves more than determining the status of their post high school employment, residential situation, and social connectedness. The impact of the transition on the family system, evidenced through the families' perceptions of the success of the transition, is an indicator of successful transition planning.

Neece et al. (2009) stated:

We wanted to explore a measure of transition success for individuals with

severe intellectual disabilities because many of the traditional indexes of successful transition may not be applicable. Because of the level of cognitive, behavioral, and sometimes physical limitations of many individuals with severe intellectual disability, along with the idiosyncratic nature of what each family considers a successful transition, we deemed it critical to assess family perspectives. Specifically, we used parent satisfaction with their young adult's transition from high school to adult life as an index of "transition success" (p. 32).

Methodology

Qualitative research, according to McDuffie and Scruggs (2008), may play a role in the implementation of research-based practices in special education. The authors further argued that qualitative research provides essential information into the effects that implementation of critical components of research-based practices have on students and their families. Implementation of mandated transition planning requirements is not sufficient to ensure an effective transition from special education services to adult services for students who have severe disabilities. A deeper examination of the process of transition planning as it is experienced by the family is called for to assist educators in implementing transition planning practices designed to foster a successful experience for both the student who has a severe disability and his or her family. Thus, the purpose of this multiple case study was to discover factors that contributed to the perceived effectiveness of the transition planning process and the perception of

family well-being, from the perspective of parents, for students who have severe disabilities.

Research Questions

The purpose for this study was to examine factors related to successful transition planning for students who have severe disabilities. Two research questions were investigated:

- What factors, from the perspective of a parent, contributed to a successful transition from secondary education services to postsecondary adult services for a student who has a severe disability?
- What factors influenced parental perception of family well-being during the transition planning process?

The first question addressed factors that influenced successful planning for changes in residence, employment, and social interactions for students who have severe disabilities during the transition from adolescence to adulthood. The second question addressed factors that contributed to parental perceptions of family well-being during the transition planning process. In the context of this study, family well-being was described as an aggregate of positive and negative indicators of individual, dyadic, and family adjustment (Blacher, 2001). As Bogdan and Biklin (2007) suggested, "Some research is relevant to issues that are of crucial importance to education or to society as a whole" (p. 58). I contended for students who have severe disabilities, the family's perceived well-

being during the transition planning process was one of these issues of crucial importance as well as an indication of the success of the planning process.

Definition of Terms

Free Appropriate Public Education (FAPE)

A provision of IDEA ensuring that students with disabilities receive necessary education and services without cost to the child or family.

Individualized Education Program (IEP).

A written plan used to delineate an individual student's current level of development and his or her learning goals, as well as to specify any accommodations, modifications, and related services that a student might need to attend school and maximize his or her learning.

Individuals With Disabilities Education Act (IDEA)

Name given in 1990 to the Education for All Handicapped Children Act (EHA) and used for all reauthorizations of the law that guarantees students with disabilities the right to a free appropriate education in the least restrictive environment.

Self-Determination

A set of behaviors that includes making decisions, choosing preferences, and practicing self-advocacy; a curriculum target for many students with disabilities, particularly those with mental retardation (intellectual disability).

Severe Disability (Disorder)

Term generally understood to describe disorders or disabilities that compromise an individual's functional skills to the extent that substantial assistance with daily living activities and ongoing supervision is required.

Special Education

Individualized education for children and youth with exceptional learning needs.

Transition Planning

In connection with special education, the development and implementation of activities designed to prepare students with disabilities for postsecondary options, such as work, college, or supported living; transition activities are individualized and are typically designed to address skills or knowledge relevant to the students' postsecondary goals.

Vocational Training and Education

Job training or employment counseling offered to students who wish to enter the work force after high school.

(Retrieved from <http://iris.peabody.vanderbilt.edu/index.html>)

Chapter 2

Review of the Literature

This review of selected professional literature begins with an historical perspective on the education of students who have severe disabilities and discussion of the rationale for and evolution of transition planning for these students. Next, three constructs essential for understanding transition planning for students who have severe disabilities, self-determination and quality of life (both for persons who have severe disabilities and their families), will be examined in light of their relationship to transition planning. An examination of theoretical perspectives on the role of the student's family in planning for transition will conclude this review.

Historical Perspectives

Educational Programming.

Effective transition planning for students who have severe disabilities may best be understood in the context of the development of public educational programming for these students. In reviewing public education for students who have severe disabilities, Winzer (1998) stated, "For many long and sad centuries, people with disabilities were outcasts of society. Political and ecclesiastical thought shunned them and society questioned their capacity for spiritual achievement and social responsibility" (p. 212). Winzer referred to previous efforts to educate students who have disabilities which included placing students in asylums, as they were called at the time.

By the close of the nineteenth century, special classes within regular public schools existed in major cities in the United States. These special classes were established for immigrant students who were not proficient in English and students who had an intellectual disability. Ferguson (1987) stated that “Public school special education emerged late in the last century in the un-graded classrooms of large cities” (p.13). During the early twentieth century, these un-graded classrooms, according to Ferguson, were sorted into classes for students deemed crippled, defective, dull, deficient, or retarded. Curriculum decisions for the lowest group of students posed no problems for educators. There were no “idiots” in public school special education classrooms. Their parents kept them home as they waited for them to develop sufficiently to attend school. (Ferguson, 1987). To further illustrate his points, Ferguson (1987) continued as follows:

With the recognition of the permanent limitations of the mentally deficient students, the content of earliest public special education quickly moved from merely slowing down the regular education curriculum to creating a specialized alternative suited to the needs of the students. While the ‘watered-down’ approach has continued through special education’s history, a competing progressive strand of curriculum alternatives has been evident since the 1920’s (p. 17).

Primarily through the efforts of parent advocacy groups, by the 1950’s the most severely disabled students began to be included in public schools. The notion that public schools bore no responsibility for the education of any disabled children began to face challenges from humanitarian advocates as well. The

prevailing thought mid-twentieth century, however, was still that the public school was not the proper location to fulfill whatever obligation society may have had in the care for severely disabled individuals (Ferguson, 1987).

Orelove and Dymond (2001) lent additional credence to these points through the following observations about the education of students who have severe disabilities.

Children with severe disabilities of course, have been with us since recorded time. Although public schools provided special education services to children with milder learning and behavioral challenges, few took it on themselves to serve the child with severe or profound intellectual disabilities, deafness, and blindness, or multiple disabilities. Most of those children who did receive educational services benefited from the hard work of parents and advocates who used church basements and other makeshift locales. It took the passage of PL. 94-142 in 1975 – which built on several key successful lawsuits – to force the states to educate all children. Many of those children stumped the educational system. There were few university teacher preparation programs to work with children with severe disabilities. No curricula or organized teaching methods existed. Moreover, more than a few administrators questioned whether or not such children belonged in public schools or if they were capable of learning. Much has changed in the past quarter century (p.107).

Evolution of Transition Planning.

Definition.

Not unlike the roots of education for students who have severe disabilities, the history of transition planning services for students who have disabilities can be traced to the mid twentieth century and arose from both programmatic and legal/regulatory efforts. Early work-study programs of the 1960's created opportunities that combined academic, social and vocational curricula along with work experience designed to prepare students for adjustment to employment after graduation (Bakken & Obiakor, 2009; Kocchar-Bryant et al., 2009).

Throughout the past century, the definition of transition planning services for students who have severe disabilities has continued to evolve along with the structure and content of the services. According to Kochhar-Bryant et al. (2009), over the past 50 years, many definitions of transition appeared in the literature. Halpern (1994) provided the field of special education with a definition of transition that is still accepted as a fundamental description of the process of growth that occurs during the period of high school completion for students who have disabilities. Halpern defined transition as follows:

Transition refers to a change in status from behaving primarily as a student to assuming emergent roles in the community. These roles include employment, participating in post-secondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult service agencies, and natural supports within the community. The foundation of transition should be laid during the

elementary and middle years, guided by the broad concept of career development. Transition planning should begin no later than age 14, and students should be encouraged, to the full extent of their capabilities, to assume a maximum amount of responsibility for such planning (p.117).

Today, research in the field of transition planning for students who have disabilities has endeavored to identify practices that will enhance the effectiveness of transition planning and, in turn, enhance the quality of life for students who have disabilities. As indicated by Kochhar-Bryant et al. (2009) and McDonnell and Hardman (2010), the past 40 years have seen the development of educational and vocational models for transition that addressed multiple dimensions of adult development.

Models.

Contemporary transition planning practices are rooted in models developed in the mid to late 1900's. The first model of significance to this study, described by Will (1983), was referred to as the Office of Special Education and Rehabilitative Services (OSERS) Bridges from School to Working Life Model. This model emphasized the importance of access to services and supports during the transition period. According to Bakken and Obiakor (2008), three assumptions comprised the foundation of the Bridges Model: first, the complexity of post school services, second, a focus on individual student needs, and, third, post school goals. Three "bridges" from school to work were defined in this model: transition without special services, transition with time-limited special

services, and transition with ongoing services that allowed disabled persons to take advantage of work opportunities (pp. 14-15).

Next, the Halpern Model (1994) addressed a full range of services and supports necessary for students with disabilities to be engaged in a comprehensive planning process for post school life. Halpern's model was comprised of three components: first, the areas of adult life that are critical for community adjustment, second, the types and level of support needed for an individual student, and third, a comprehensive planning process (Bakken & Obiakor, 2008, p. 15; McDonnell & Hardman 2010, pp. 18-20).

Kohler and Field (2003) described a model for conceptualizing transition based on the premise that all education is education for transition. Kohler and Field described effective transition practices in five areas: student-focused planning, student development, collaboration with agencies, involvement of the family, and structures within programs. Kohler and Field contributed to the understanding that packaged transition planning does not work and that, according to the authors, "Through continued attention to the establishing of effective transition services flexible enough to meet individual student needs, we can arm students with information and opportunities on which they can build their futures" (p. 8).

Outcomes of Transition Planning

Two factors may be considered central to determining the success of transition planning for students who have severe disabilities: student quality of life and family quality of life (Blacher, 2001; Chambers, Hughes, & Carter, 2004;

Kraemer & Blacher, 2001; Neece et al., 2009). The purpose for transition planning is simple: it constitutes a plan for assisting a student who has just completed high school to secure a meaningful job and a satisfactory residential situation, obtain financial support, find reliable transportation, and maintain a network of social relationships that all contribute to that young person's quality of life. The family's quality of life, in turn, may be influenced by the quality of life of the individual who has a severe disability; a premise that informs this study (McIntyre, Kraemer, Blacher, & Zimmerman, 2004). One additional outcome, the use of quality of life indicators as evidence of program effectiveness, continues to gain acceptance in the research community and will be discussed in relationship to this study.

Student Quality of Life.

Flexor et al. (2008) reviewed the concept of quality of life as a valid outcome measure for the field of special education. The authors credited the outcome-oriented focus of education with forcing special educators to think about special education services in ways that could be measured. Halpern's (1993) study is attributed with first applying quality of life measures to outcomes research (McDonnell & Hardman, 2010). Shalock (1997) reviewed the history of the development of the concept of quality of life through the lens of its application to persons who have an intellectual disability. Shalock's review posited that the construct of quality of life is based on two premises. First the concept of quality of life is a social construct that affects program development and service delivery,

and, second, the concept of quality of life can be used as an outcome measure for assessing service delivery.

Much additional study has been devoted to defining the concept of quality of life for persons who have severe disabilities. Core dimensions that comprise quality of life identified throughout the literature include physical well-being, material well-being, social inclusion, interpersonal relations, self-determination, personal development, and emotional well-being. It is established that quality of life is an outcome for services provided for persons who have severe disabilities (Kraemer & Blacher, 2001; Kraemer et al., 2003; Seltzer & Kraus, 2001; Turnbull et al, 2003).

In addition to quality of life as an outcome, Turnbull, Turnbull, Wehmeyer, and Park (2003) argued that the four outcomes identified by IDEA for all special education services (equality of opportunity, full participation, independent living, and economic self-sufficiency) should guide educators to a broader goal of enhancing the quality of life for students who have disabilities. Turnbull et al. acknowledged the challenges faced by the research community in defining quality of life and its role as an outcome measure and stated, "There needs to be a reconciliation between emphasis placed on achievement in academic subjects and the accomplishment of quality of life results tied to IDEA's four goals" (p. 7.)

McIntyre et al. (2004) studied mothers' perspectives on the quality of life for their son or daughter during the process of transition. As indicators relating to quality of life, participants in this study mentioned "having basic needs met,

having a social network, and the attainment of general happiness or well-being” (p. 142).

Family Quality of Life.

Studies have described family quality of life as a valid outcome for services that are provided for families who have children with disabilities. Brown, Schalock, and Brown (2009) argued that individual and family quality of life are closely intertwined. “With disability in the family, dynamics generally shift from interaction among family members to a focus on the person with a disability, frequently with unfortunate consequences” (p. 4).

Summers, Poston, Turnbull, Marquis, Hoffman, Mannan, and Wang (2005) offered a means for assessing the concept of family quality of life and identified factors that appeared to contribute to quality of life. Summers et al. posited that family quality of life may be assessed through examination of “...opportunities for participation, their initiative in taking advantage of opportunities, their attainment in accomplishing things important to them, and their satisfaction with their overall family life” (p. 779). The authors reported that based on interviews with families who have children ages 10-36, family relationships, spiritual/cultural beliefs, and careers appeared to be strong contributors to family quality of life. Families expressed lower satisfaction with the lack of practical support extended by family, friends, and neighbors and with opportunities for leisure time as a family. They also expressed frustration with disability services that did not always appropriately address their priority needs. (p. 779).

Summers et al. (2005) identified needs for further research into both policy and practice regarding family quality of life. The authors stated, “Agencies generally are required to report on the outcomes or impact of their services to justify continued funding. Quality of life outcome data are an appropriate accountability index for agencies providing supports and services to families” (p. 78).

Educational Program Effectiveness.

Why plan for transition for any high school student? Moreover, why plan for the transition of students who have severe disabilities most of whom will require life-long support for managing their day-to-day lives? Kochhar-Bryant et al. (2009) addressed the question from the perspective of assessing the effectiveness of services provided in the public school setting. The authors asserted, “Successful transition from secondary education is becoming recognized as a chief indicator of the effectiveness of our educational system for preparing young adults for employment, postsecondary education, and adult independence” (p. 9).

The authors further argued that, “A greater national investment is being made to assist all individuals to access education and employment preparation programs and increase social and economic independence” (p. 9). According to Bakken and Obiakor (2008) educators view the attainment of post school outcomes as a measure of the effectiveness of transition planning. In the authors’ words, “The goal of transition services is to assist students with

disabilities to achieve their career and life goals, as well as become active members of their communities” (p. 5).

Bakken and Obiakor (2008) continued, “This transition from school to work is essential to ensure positive post school outcomes for students with disabilities” (p. 3-4). The authors argued that effective transition planning improves the attainment of post school outcomes, makes education more meaningful for students, and enhances students’ abilities to exert influence over their progress toward goals. According to Bakken and Obiakor, “The federal requirements for transition services grew out of a perceived need based on this research regarding post school outcomes of students with disabilities” (p. 4).

Developing Effective Transition Plans

Effective transition planning for students who have severe disabilities must be designed around the strengths, needs, and preferences of the student. For students who have severe disabilities, recognizing their strengths, needs, and preferences may necessarily involve their parents or guardians. Even the most severely disabled students, however, have preferences and building upon their preferences will enhance the effectiveness of the transition plan. Two factors become intertwined when planning for transition for students who have severe disabilities: the student’s own ability to exhibit self-determination and, second, parental participation (Bakken & Obiakor, 2009, McDonnell & Hardman, 2010).

Self-Determination for Students Who Have Severe Disabilities.

The concept of self-determination appears throughout the literature as a construct fundamental to any discussion of transition planning for students who

have severe disabilities (Agran & Hughes, 2005; Eisenman, 2007; Shevin & Klein, 2004). The theoretical perspective of this study is built upon the thinking that the student and his or her family guide the transition planning process. Practice in choice-making is critical for students who have severe disabilities to enable them to participate in decision making related to transition planning.

From an historical perspective, the research has suggested two key concepts: first, that persons who have severe disabilities can learn to be self-determined and, second, further study in determining effective practices for teaching and supporting self-determination skills is needed. Agran and Hughes (2005) stated that “Despite an overwhelming professional acceptance of the concept of self-determination and a growing body of research to document its positive effects, the available data suggest that relatively few people with severe disabilities are being supported to become self-determined” (p.106).

Several key concepts play into both the construct of self-determination and the resulting instructional models necessary for fostering self-determination. These concepts include teaching students how to regulate their own behavior through goal-setting, self-monitoring, evaluating their behavior against an existing standard, and learning from mistakes and adjusting goals and performance (Shevin & Klein, 2004). Self-determination is about the process of having a minimum of three desirable options from which to choose and the process of engaging in choosing from these options. Shevin and Klein defined choice-making for persons with severe disabilities as the “act of an individual’s selection of a preferred alternative from among several familiar options” (p. 162).

Understanding the ability of students who have severe disabilities to report on their own perception is limited by the persons' ability to communicate and self-report on their own perceptions. Professionals, in general, negate the importance of self-determination for persons who have severe disabilities as compared to persons who have milder impairments. One of the barriers to effectively instructing students in choice-making lies in educator's perceptions that self-determination is an idea, not a set of skills that can be mastered (Wehmeyer, 2005).

Wehmeyer (2005) further contended that, of all the misinterpretations around self-determination, perhaps the most destructive is the attempt to equate self-determination with control. Persons who have severe disabilities have no more control over the outcome of self-initiated action than do persons who do not have a disability. Wehmeyer called for a rethinking of self-determination from that of control to volitional behavior. Wehmeyer stated, "Self-determination refers to people acting volitionally, based on their own will. *Is this applicable for people with severe disabilities?* The answer is yes: people with severe disabilities can be supported to act more volitionally" (p. 117). Wehmeyer concluded with the following statements:

Organisms, human beings included, are autonomous entities.

Autonomous beings are self-regulating, self-directed, and to a lesser or greater extent, self-determined. I suggest that there is not a single being who is not, to some degree, self-determined. For people with severe disabilities, limitations in personal ability, opportunities, the perceptions of

others, and the environments in which they live, learn, work, or play limit the degree to which they can become more self-determined. The role of teachers is not to teach students to control their lives. It is to enable students with severe disabilities to become more self-determined, even if it is just a little bit more. We can achieve this by enabling students to express preferences, by implementing instruction that promotes involvement in problem-solving and decision making, and by promoting self-advocacy and student-directed learning. The goal is not to promote control, but to enable students to act volitionally and to become causal agents in their lives, to make things happen in their lives (p.120).

The concept of self-determination within the context of family dynamics is key in understanding the premise of this study. Communication limitations for these students often limit input into decisions affecting their lives. For young adults who have severe disabilities, self-determination often includes some level of external influence exerted by the people in their lives who provide support for decision-making. Thus, parents and guardians remain crucial figures in the transition planning process. Kim and Turnbull (2004) asserted that, "Self-determined persons choose how to live life consistent with their own personal choices and preferences ..." (p. 55). The authors continued, "However, individuals with severe intellectual disabilities may have cognitive and functional limitations in independently making some quality of life decisions, and in these circumstances, may need to rely on a variety of supports" (p. 55).

Zhang (2005) examined factors that influenced parental support of self-determination for youngsters who have severe disabilities. Zhang reported that cultural norms play into the family's beliefs regarding individualism as opposed to collectivism. These beliefs influenced the family's perception of the relative importance of self-determination and, in turn, the family's perspective on transition planning.

Zhang (2005) studied 136 parents of individuals with disabilities yielded the following information. Culture, length of time living in the U.S., gender, special education status, and socioeconomic status all exerted an influence on children's personal independence as evidenced by the family's behavior regarding household tasks, interactions with others in the environments, and parenting style. These culturally influenced differences in perspective and resulting behavior must be considered in studies involving the effectiveness of transition planning. In essence, factors that might be viewed as effective planning for one family may be viewed differently by another family.

Martin, Woods, Sylvester, and Gardner (2005) examined the match between the vocational choices made by young adults who have severe disabilities and the choices caregivers made on their behalf. The results of this study indicated that the choices made by individuals differed from those made by caregivers on their behalf. Further, the authors concluded from this study that, given the means and the practice to engage in meaningful choice-making regarding job setting and activities, that individuals who have severe disabilities

would make choices based on preference and that these choices are not often congruent with caregiver choices.

The implications of this study are particularly relevant for professionals as they engage in the process of transition planning for students who have severe disabilities. Martin et al. (2005) argued that, consistent with the context of this study, “participants and caregivers provided unsolicited but relevant comments supporting the findings of this study and the practical applications” (p. 152). Given a reliable method for eliciting input from their youngster, the authors suggest that parents would have utilized this information as a key part of the transition planning process. A much broader implication of this study is that utilizing methods for effectively communicating with persons who have severe disabilities is crucial in enhancing their ability to make choices regarding their lives.

Parental Involvement.

Family Systems Theory.

Family systems theory provides a framework for understanding the interrelatedness of the quality of life for individuals with severe disabilities and their families especially during the transition from high school to adult life and supports the premise behind this study. Specifically, the well-being of the family is a valid outcome measure of the effectiveness of the transition planning process. Zuna, Turnbull, and Summers (2009) posited that variables interplay to affect family quality of life and that a theoretical model for understanding family quality of life was necessary for practitioners to understand how to manipulate

the variables to enhance quality of life. The authors identify three components that interact to influence family quality of life: systems, policies, and programs. The application of their theoretical model to transition planning is self-evident. Zuna et al. stated,

Systems are a collection of interrelated networks organized to meet the various needs of society, such as healthcare, education and legal systems. Policies are guidelines establishing, organizing, and regulating the procedures for implementing programs and systems. Programs are formally and informally organized entities that provide services and supports to an identified population (p. 27).

McDonnell and Hardman (2010) argued that viewing the family within a systems perspective would assist educators in understanding the unique challenges faced by individual families as they plan for transition. Three key points made by the authors are as follows: individuals interact with each other within the system to create the system, the system can be best understood as a whole, and boundaries develop both within and around the family system and will influence the operation of the system. In addition, Kocchar-Bryant et al. (2009) stated that implementing effective transition planning involves processes more complex and involved than those mandated in the law. "Facilitative processes mean practices that state and local educational agencies have developed over the years as a result of their students' experiences with transition under IDEA and their own evaluation of services" (pp. 32-33).

The IDEA requirement - the development of a comprehensive transition plan as part of each student's IEP, does not necessarily translate into provision of supports and services adequate to assist students in meeting their identified post school outcomes. Investigations have identified significant challenges within the secondary education system in meeting mandated requirements (Sabbatino & Macrine, 2007; Johnson et al., 2002). Additionally, Johnson et al. asserted that the "Areas of greatest noncompliance include having appropriate participants at IEP meetings, providing adequate notice of meetings, and providing a statement of needed services in student's IEP's" (p. 521).

Johnson et al. (2002) further stated, "Limited levels of service coordination and collaboration among schools and community service agencies create difficulties for students with disabilities and families in achieving post school goals." (p. 521). deFur (2003) concurred and asserted that research conducted prior to the authorization of IDEA 2004 indicated that minimum technical IEP requirements were being met but, meeting technical requirements did not translate into effective planning.

McDonnell and Hardman (2010) further stated, "There is consistent evidence from more than three decades of research that family members' involvement in their children's education results in improved student outcomes" (p. 117). The authors continued with this statement.

In spite of the consistency of research findings concerning the importance of parent involvement for a variety of student outcomes, many of the studies do not include families of students with disabilities, and family

involvement has been more frequently studied for elementary students than for secondary students (p. 117).

McDonnell and Hardman (2010) cited the Council for Exceptional Children's (2001) position that " Although the research base is somewhat limited regarding students with disabilities and their families, there is every reason to believe that family participation is at least as important in the attainment of a variety of outcomes for students with disabilities" (p. 117). In summarizing Kim and Turnbull's (2004) work, McDonnell and Hardman (2010) made the following statement:

Family participation and involvement in transition planning may be especially crucial in determining ongoing adult quality of life for individuals with intellectual and developmental disabilities, for whom complete independence in all areas of adult life may not be a realistic goal. Many young adults with intellectual or developmental disabilities will continue to live at home with their families for a number of years, making an interrelated quality of life even more evident and important to consider (p. 117).

Families of students who have severe disabilities face multiple sources of stress during the period of transition. According to Ankeny et al. (2009). "They typically piece together support networks, invest personal resources, and juggle multiple roles and responsibilities to help their children achieve fulfilling futures. Current service delivery models place families in a central role in determining services..." (p. 28).

Effective transition planning for students who have severe disabilities is a complex undertaking. Neece et al. (2009) reported that research has focused on assessing effectiveness of transition planning through the studies of vocational placements, social interactions, residential situations, and quality of life studies. Because of cognitive and communication limitations of young adults with severe intellectual disability, much of our understanding of their transition experience depends on parents' perspectives and contributions. The authors stated, "Little research has been conducted examining how the transition process affects families, beyond expectations, even though researchers have found that families, not just the individual with an intellectual disability are affected by transitions. There is limited empirical research on families during the transition period" (p. 32).

Ankeny et al. (2009) argued that families are often placed in the role of providing back up services for their children, and that families often serve as the one consistent source of support for their adult children. Ankeny et al. stated, "In reality, no one agency provides all the necessary services for an adult with a disability." (p. 31). The authors further asserted that families need support from educators to develop the skills necessary to manage the system of adult support services.

Chambers et al. (2004) asserted the following:

Given that students, parents, siblings, and other family members are all affected by the transition process and its outcomes, these individuals should be collaborative partners in transition planning and decision

making. In addition, because the support networks of persons with significant disabilities typically are composed of family members, it is important to identify families' involvement in the transition process and families' perceptions of transition outcomes to determine post school outcomes that are valued. This information could guide transition teams in developing goals that are supported by family members (p. 80).

Chambers et al. (2004) found that family members indicated that both independent residential situations and employment were highly valued transition outcomes. Further findings reported from this study indicated that family members were very concerned about the social life of their son or daughter upon transition from high school. Of note is the fact that this study included sibling perspectives on the process of transition for their brother or sister.

McIntyre et al. (2004) studied mothers' perceptions of the quality of life for their transition-aged son or daughter. The authors asserted that when considering the quality of life for a young person who has a severe disability, family involvement is critical. McIntyre et al. asserted that, "With transition-aged young adults, the family's role may be typified by the living environment and the involvement they have in the young person's life." (p. 133). Findings of this study indicated that mothers identified quality of life for their son or daughter through having various factors including but not limited to having basic needs met, involvement in recreation activities, and having a social network. McIntyre et al. continued, "These data suggested that mothers considered their son or daughter's current living situation and available environmental supports when

describing quality of life, although more empirical work is warranted.” (pp. 142-143). The authors concluded that “there appears to be a disconnect between special education policies and mandates in the United States and the desires of families of young adults with severe disabilities.” (p. 143).

McIntyre et al. (2004) argued that the focus on vocational outcomes as well as the emphasis on self-determination and autonomy could be incongruent for students who have severe disabilities. “These viewpoints may be incontestable from a philosophical, humanistic or inclusive point of view. However, they are predicated upon a certain level of cognitive ability in the young adult and, to some extent, the desire and energy of the young adult’s parents or care providers” (p. 143). The authors call for a reexamination of the definition of transition success for students who have severe disabilities.

How do we know if students who have severe disabilities have had an effective transition plan developed for them? How can educators determine if their transition has been successful? It is not through commonly accepted means such as surveying their residential or employment status. It may be through simply asking the question, “What works best for your family?”

Indicators of Successful Transition Planning

Research examining effective transition planning for students who have disabilities, mild and moderate disabilities as well as severe disabilities, initially utilized employment as a defining characteristic of the effectiveness of the transition planning process. Eisenman (2003) described a theoretical basis for transition planning based on the premise that employment remains a widely

accepted indicator of a successful adult life for persons who do and do not have a disabling condition. Eisenman argued the following:

Being employed is just one valued adult role, but it is a primary indicator of adult success in the United States. Helping students with disabilities to secure post school employment is a central focus of special educators concerned with school to adult life transition. Those in the special education transition field continue to emphasize accountability for post school outcomes, including employment (p.1).

Cobb and Alwell (2007) discussed the relative importance of employment as an indicator of a successful adult life. They reiterated that Halpern's (1994) definition of transition included multiple components of post high school status that indicated a successful transition had been accomplished. These components included not merely employment, but participation in postsecondary education, maintaining a home, becoming appropriately involved in the community and experiencing satisfactory personal and social relationships. Eisenman (2003) broadened the discussion of factors contributing to post high school success with the following assertion:

The special education transition field is pragmatically focused on solving culturally and socially determined problems (e.g. employment, graduation) that span multiple environments (educational, vocational, residential and community) and involve multiple factors, including both individuals (e.g. children, young adults, family members, teachers, employers, social service workers) and corporations(e.g. school systems, community

services, businesses, families) whose intrinsic and socially defined characteristics interact across time (p.8).

Eisenman (2003) also suggested that future research into transition needed to occur at three levels: broad studies of large structures in the field in relationship to other structures; studies of relationships within fields (e.g. relationships, values and operations among the institutions and agents within and across contexts); and, third, analytic studies of backgrounds, experiences and dispositions of students, families, and educators as they interact within the field. This study endeavored to address Eisenman's third identified area for further research- experiences and dispositions of families.

Additional studies indicated that parents or guardians play a critical role in the ultimate effectiveness of the transition process and that the mere procurement of employment may not be a satisfactory indication of the success or failure of the transition planning process. Cobb and Alwell (2007) contended that despite our empirical and theoretical knowledge, "It seems our greatest need is in applying what we know - informing and supporting practitioners and families in a uniform fashion so that implementation of effective transition practices for youth with disabilities might become more commonplace" (p. 41).

Getzel and deFur (1997) studied transition planning for students with severe disabilities and concluded that there is a "need for greater participation in the planning of their future, opportunities to access employment prior to exiting school, and access to a range of services to provide on-going and long-term support in the community" (p.48). The authors contended that "Family

involvement in transition planning for students with significant disabilities is critical, because families may be their one on-going and consistent source of support” (p. 46). Gallivan-Fenlon (1994) concluded that young adults and their families are often not full participants in the transition planning process and experiences are less than successful in making the transition. The author’s additional findings determined that collaboration involving community agency involvement is essential in planning; a person who assumes the role of coordinator for the team is crucial; and rhetoric does not translate into reality as far as services for adults are concerned.

Theoretical Basis for this Study

Building upon the knowledge I gained through reviewing the literature related to transition planning and with the premise that perceived quality of life for both the individual student and his or her family is a valid measure of transition planning effectiveness, I would argue that the work of three researchers informed the theoretical perspective for this study.

Kim and Turnbull.

To begin, Kim and Turnbull (2004) merged two existing theoretical models of transition planning, person-centered and family-centered planning models into their theory described as Person-Family Centered Interdependent Planning. The authors argued that neither person-centered planning nor family-centered planning alone addressed the needs of both the individual and his or her family. The authors stressed the interconnectedness of individuals who have severe disabilities and their families both during and after the transition period and

argued that transition is a stressful time of life for the both the individual who has a severe disability as well as his or her family. Further, Kim and Turnbull asserted that the quality of life for both the individual and the family is affected by the process of transitioning and efforts to address the quality of life for an individual must take into consideration the quality of life for the family as well.

The authors made the following comparison:

The relationship between young adults, especially those with intellectual disabilities, and their families can be compared to a pair of chopsticks. One of a pair of chopsticks can function alone by poking foods such as meatballs, but it still needs the other of the pair to handle difficult food challenges such as spaghetti. For the use of its full capacity, the chopsticks must work as a pair since they function best when acting interdependently (p. 55).

Kim and Turnbull (2004) argued that the family system is affected by the transition process and that students who have severe disabilities often experience more stressful transitions than their less severely disabled peers, in part, because of the limitations of available community resources. Kim and Turnbull reinforced the notion that the family's understanding of quality of life must be taken into account when assessing the success of a transition experience.

Kim and Turnbull's (2004) theory was built on five principles. First, transition for a young adult with severe disabilities is influenced by and, in turn, influences the family system. Variables within the family system influenced the

family's reaction to and assessment of the transition process. Second, young adults who have severe disabilities and their families had choices about the direction of their lives. Third, for young adults who have severe disabilities, self-determination includes some level of external influence exerted by the people in their lives who provide support for decision-making. In addition, the family's culture influences their perceptions of self-determination for the individual who has a disability. Fourth, transition plans need to consider the needs of the family as well as the needs of the individual. Fifth, there is a need for enhanced policies and programs that provide social, emotional and financial support for families as their son or daughter transitions from secondary education to adult life. Kim and Turnbull's model provided a means for educators and service providers to think about transition into adulthood from the perspective of persons with disabilities, their parents, and other family members.

Blacher.

The second theorist, Blacher (2001) proposed a conceptual model for investigating the transition to adulthood for young adults who have an intellectual disability. According to the author, although there have been many previous studies of transition, the author's model considered transition from a family perspective with family well-being as the primary outcome of interest. "A direct relationship between transition success and family well-being is proposed here" (Blacher, 2001, p. 179.)

Blacher's (2001) conceptual model was intended to guide the study of family well-being during the period when students who have disabilities are

engaged in the transition from late adolescence to adulthood. The developmental period is critical in that formal schooling ends and change in residential, vocational and social status are likely. Blacher proposed that the success of transition experiences would influence family well-being. Family well-being, according to Blacher, is an outcome of primary interest in assessing the effectiveness of transition planning.

Blacher (2001) continued as follows:

A second outcome domain is transition success. I hypothesize that during this period, a major influence on family well-being is the extent to which transition outcomes are viewed by individuals served and their family members as positive and successful. It is important, then to identify factors, which, beyond transition success, influence family well-being (p. 74).

Blacher's (2001) theoretical perspective remains critical to understanding transition for students who have severe disabilities and informed the theoretical basis for this study. Blacher's premise is that, for youngsters who have an intellectual disability, and this researcher argued, other severe disabilities, family well-being is a valid outcome measure for determining the effectiveness transition planning. Blacher defined family well-being as "An aggregate of positive and negative indicators of individual, dyadic, and family adjustment" (p. 174). Blacher described successful transition as meeting any "desired outcome in the areas of residence, education, employment, or social environment" (p. 178).

Blacher (2001) cited Ferguson, Ferguson and Jones (1988), who offered the caution that "successful program outcomes did not guarantee successful

outcomes for the family” (p. 183). Blacher asserted that family well-being may be understood by the extent to which transition outcomes are viewed by both the student served and the family as having been successfully accomplished.

Consistent with other theoretical perspectives, Blacher embraced the hypothesis that individual characteristics of the child affect both transition success and family well-being. Blacher offered a conceptual understanding of the interplay among four sets of factors- characteristics of the individual student, family environment and culture, involvement and/or detachment, and success in accomplishing transition outcomes that exert influence on the well-being of the family.

Transition affects the family of a student who has a severe disability in immediate and profound ways. Family well-being, therefore, Blacher (2001) argued, may well serve as an outcome variable during the transition process for students who have severe disabilities. Blacher hypothesized that individual characteristics of the child influenced transition success and family well-being and that family resources are important predictors of transition success. This period is critical because it is the phase of a young person’s life that sets the stage for adulthood. Starting off on the right foot through successfully transitioning to adult employment or residential situations establishes the young person and his or her family in the adult service system. Blacher argued as follows:

This transition to adulthood is a time of heightened opportunities but also of new risks. These challenges relate to the individual, the family, and the social service system. For example, the individual who has an intellectual

disability may seek increased independence. Indeed, vocational and adaptive programs for high school students with severe disabilities often reflect goals of autonomy and self-determination. Yet, this is also a time when the young adult is at heightened risk for behavioral and psychiatric disturbances. In the normative case, the family system changes as well, as other children go off to college or jobs and move out of the family home. Perhaps most crucial during this period is that public school funding ceases, and the quest for appropriate programs begins anew. Thus, the period is marked by growth and change but also by increased uncertainties and challenges, and it is important to better understand the experience of persons and families going through this transitional period. Empirical study of family experiences, problems, and needs should “fill the gap” in the transition to adulthood theoretically and lead to more responsive services (pp.173-174).

Blacher (2001) contended that because the family and the student remain tightly connected, that family satisfaction with transition planning as evidenced by their perception of family well-being throughout the process may be a more valid measure of transition success than achieving post school goals for employment and residential situation.

Neece, Kraemer, and Blacher.

Neece, Kraemer, and Blacher (2009) examined the effect of perceived family stress during transition and the effects of this stress on the perception of the effectiveness of transition planning. The authors contend that research has

shown this transition period to be especially stressful and difficult time for young adults who have intellectual disabilities and their families. The authors asserted that little research has been conducted examining how the transition process affects families beyond expectations for the transition even though researchers have found that this transition affects families not just the individual. The authors asserted, "To date, little research has examined how transition will affect family well-being." (p. 32)

Neece et al. (2009) explored a measure of transition success for individuals with severe disabilities. The authors argued that many of the traditional indexes of successful transition may not be applicable for students who have severe disabilities. The cognitive, behavioral, and sometimes physical limitations of many individuals with severe disabilities, along with the idiosyncratic nature of what each family considers a successful transition, makes it necessary to assess the family's perspectives. Neece et al. stated:

Specifically, we used parent satisfaction with their young adult's transition from high school to adult life as an index of transition success. Second, we wanted to examine the relationship between transition satisfaction and family well-being. However, the extent to which well-being of the family is influenced by a successful transition of the child with an intellectual disability is unknown (p. 32.)

Parental satisfaction with their involvement in transition planning was a key variable in the investigation conducted by Neece et al. (2009) and was related to overall transition satisfaction. The authors asserted the following:

This study confirms that family involvement in transition planning affects the overall satisfaction of the family and more successful outcomes. We do not know the direction of the relationship between transition satisfaction and family involvement in planning. We do know that there is a relationship between what service providers do and how satisfied parents feel (p. 40).

Neece et al. (2009) contributed to the existing literature by exploring a unique indicator of transition success, examined predictors of a successful transition, and investigated the relationship between transition success and family well-being. According to Neece et al.:

Given the limited empirical research on families during the transition period, future work must continue to examine the implications of the young adult transition outcomes for family well being. Future work should continue to examine additional ways of measuring transition success for young adults with severe intellectual disability. (p. 41)

The Role of Qualitative Methodology in the Study of Transition Planning

Neece et al.(2001) called for examining additional ways in measuring transition success for students who have severe disabilities. The use of qualitative methodology in the field of special education will be explored in greater depth in Chapter 3, but it is evident that qualitative studies have contributed depth to the literature on transition planning for students who have

severe disabilities. Of particular interest is the use of qualitative methodology to investigate the transition experiences of families of culturally diverse backgrounds. Rueda, Monzo, Shapiro, Gomez, and Blacher (2005) investigated the experiences of Latina mothers. Rueda et al. used focus groups to examine culturally based differences in beliefs about the process of transition. Mueller, Milian, and Lopez (2009) interviewed eight Latina mothers who were involved in parent support groups and determined that information sharing was an important component of the group and often provided information not available from the school.

Kyeong-Hwa, Youngsun, and Morningstar (2007) interviewed Korean-American parents regarding their perceptions and experiences during the transition process. From their findings, Kyeong-Hwa et al. concluded that the parents in this study considered the disability system and services in the United States as a factor that facilitated their child's future in a positive way. Professionals' negative attitudes were mentioned as a major barrier to fulfilling their hopes for their child's future. The Korean-American parents emphasized "special hearts" as a quality that all professionals working with students with disabilities should have. The authors reported that this finding is consistent with other research indicating that teachers who listened to families and facilitated their connections with other families of secondary students were considered to make the most difference.

Kyeong-Hwa et al. (2007) stated five implications for professional practice that the researcher hypothesized would emerge from their study. The authors

advised professionals that transition experiences for families who are CLD (culturally or linguistically diverse) would be enhanced by knowing their (the professional's) own world view, learning about the families in the community, respecting cultural differences, and reaching mutually agreed upon goals.

The current study investigated the transition experiences of three families whose children were enrolled in a special school serving only students who have severe disabilities. While all three families share the same cultural background, the experience of attendance at this special school places them in a unique situation within their community. Their experiences are explored in Chapters 4 and 5 of this study.

Chapter 3

Methodology

In Chapter 1 of this study I reviewed the issues that are related to the transition from adolescence to adulthood for students who have severe disabilities. In Chapter 2 I summarized the professional literature regarding transition for students who have severe disabilities. This review and summary of the literature provided support for the need for additional investigations in the area of transition for students who have severe disabilities to determine factors that influence the quality of life for the student and the family during this time of transition. The literature supports the assertion that the family's quality of life or well-being may serve as an indication of program effectiveness.

Two questions guided this study. First, from the parents' perspective, what factors contributed to a successful transition from secondary education services to postsecondary services for a student who has a severe disability? Second, during the transition planning process, what factors influenced the perceived well-being of the families of students who have severe disabilities? A multiple case study methodology was utilized for this investigation. Chapter 3 provides an explanation of the instrumentation, data collection and data analysis utilized in conducting this study.

Qualitative Methodology in Special Education Research

There is a long established recognition of the value of qualitative research methods in addressing research questions in special education. Over 20 years

ago, Hegarty and Evans (1985) argued for the utility of qualitative research in the field of special education. Similarly, Ferguson (1993) proposed that qualitative research provides advantages for gathering and analyzing data as well as establishing a worldview of the nature of knowledge and inquiry. Recently, Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2007) have advocated for qualitative research as a “systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context” (p.195). The authors argued that qualitative designs produce science-based evidence that can inform policy and practice in special education and asserted that qualitative research attempts to answer questions about what, why, and how a phenomenon, such as a successful transition from high school to adult services, occurs. Brantlinger et al. (2007) offered that “Qualitative research may lead to a deeper understanding of individuals with disabilities, their families, and those who work with them” (p.196). In summary, the literature has consistently advocated for qualitative studies as an effective approach to explore the nature and extent to which a practice has a constructive impact on individuals with disabilities, their families, or on settings where they tend to work, reside, or are educated.

Beyond the general appropriateness and utility of qualitative approaches to special education research, the method is also conducive to narrative descriptions that can help frame some of the complicated transitional issues faced by students who have severe disabilities and their families. For example, Pugach (2001) argued that the way the field of special education chooses to interpret the qualitative research paradigm determines the influence this

approach has on the fundamental understanding of phenomena within the field. According to Pugach, qualitative studies inform our collective understanding about effective ways to improve education for students with disabilities. Pugach stated that “It is often by telling stories that educators, as well as the public at large, have come to understand the needs of persons with disabilities” (p. 439).

Pugach (2001) further stated that the qualitative paradigm allows us to ask not only different questions, but to “ask questions differently” in ways that help us capture the complex life experiences of individuals with disabilities.

Qualitative research is not simply an alternative method for studying disability. Experience is socially constructed and our knowledge and experience of disability exists within these social constructs. Relying on qualitative research, special education scholars have a means to study important, complex problems that face the field and to tell disciplined stories that appropriately capture this complexity (p. 446).

This same richness and depth of description that qualitative methods bring to our understanding of the experiences of individuals with disabilities and their families also facilitates our ability to evaluate the impact of programs and services. Qualitative research methods allow for understanding disability in a powerful and enlightening way through investigating how and why special education practices impact students. Qualitative research can play a role in the implementation of research-based practices in special education (McDuffie and Scruggs, 2008). Qualitative research provides in-depth information into the effects that implementation of critical components of research-based practices

have on students and their families. In line with the purpose of this study, a qualitative methodology provided an approach that improved my chances of discovering factors contributing to the perceived effectiveness of the transition planning process. Using this approach, I examined this process from the perspective of parents of students who have severe disabilities.

Theoretical Perspective for This Study

I approached this study from a pragmatic perspective; the purpose of this study was the attainment of in-depth knowledge related to transition for students who have severe disabilities. This research approach contributed to a more comprehensive understanding of how special education professionals can support individuals who have severe disabilities and their families during the process of planning for transition from high school to the adult world. The theoretical base for this pragmatic research approach is described in the work of Creswell (2009), who has advocated for approaching research in the context of one's worldview and philosophy. Creswell discussed the concept of the researcher's worldview in terms of his or her orientation to the world as well as to research itself. In this context, a pragmatic researcher is one who has a fundamental concern with how the acquired knowledge may be applied to create solutions to problems. The pragmatic researcher, according to Creswell, looks to answer what and how questions based on the intended consequences – where they want to go with the conclusions of their research.

Rationale for a descriptive multiple case study.

Having determined that a qualitative approach would be the most appropriate avenue for this study, I turned to the question of a specific research design. After some review, I determined that a multiple case study design would be the most appropriate for a study of the transition to adulthood for students who have severe disabilities. It was also appropriate for addressing the research questions of the study. This approach to research design is well established in the field of education and seemed to be a particularly fitting approach for the focus of this study. According to Merriam (1998) a case study design may be employed to gain an in-depth understanding of the situation and meaning for those involved. Merriam argued that in a case study investigation, the interest is in process rather than outcomes, in context rather than a specific variable, in discovery rather than confirmation. In a similar vein, Yin (2009) argued that researchers investigating how and why questions often select a case study methodology. He observed that the case study may be preferred when examining contemporary events and for research where relevant behaviors cannot be manipulated. In addition, Yin argued for the utility of case studies incorporating direct observations and interviews. In addition, Gerring (2007) explained that in a case study investigation, the researcher should not expect that the cases perfectly represent the entire population under study, but provide insight into the phenomenon being investigated.

A more precise description of the methodology of this design may be found in the work of Creswell (2009). He referred to case study methodology as a strategy of inquiry in which the researcher explores in-depth a program, event,

activity, process or one or more individuals. According to Creswell, cases are bounded by time and location and researchers may use a variety of data collection procedures. The case study approach is particularly appropriate in contexts where a researcher wishes to investigate a contemporary phenomenon in depth and within its real life context as I did in this investigation.

According to Yin (2009), a case study method is particularly useful when distinctive boundaries between phenomenon and context are not clearly evident. I would argue that transition planning lies within these boundaries; that is, the experiences of families are defined in part by the contexts of their larger communities and the schools their students attend. Based upon my review of the state of knowledge regarding the focus of this research, I selected a multiple case study approach for this investigation.

In summary, I deemed a multiple case study methodology appropriate for this investigation because my purpose was to understand the perspectives of parents as they participated in transition planning for their son or daughter. McDuffie and Scruggs (2008) asserted that since qualitative research is based primarily on the perceptions of participants and the observations of researchers, it may potentially assist in uncovering contextual factors that contribute to success or failure of educational practices.

Site Selection and Participants

I selected a special school in a small Midwestern city that serves only students who have severe disabilities as the setting for this investigation. This special school site was selected through professional references and provided

me with a sample of convenience. I chose this site based upon the thinking of researchers regarding site selection for a qualitative investigation. According to Merriam (1998), "Sample selection in qualitative research is usually (but not always) nonrandom, purposeful, and small (p.8). Bogdan and Biklin (2007) described case study research as a detailed examination of one setting. Creswell (2009) argued that qualitative researchers ought to identify a purposefully selected site and participants for an investigation. He noted that the purposeful selection of a site would aid the researcher in best understanding the research problem or question.

The current administrator of the school facilitated access to the families and served as the gatekeeper for the research. Creswell (2009) has noted the necessity for gaining the approval of gatekeepers at a research site to allow or permit the research to be undertaken. Permission for this investigation was granted through the intermediate service agency responsible for the school operations and involved first obtaining permission from the Drake University Institutional Review Board.

The pool of potential participants for this study, families who had a son or daughter who was currently attending or had graduated from this school, was limited by several factors. These factors included the relatively small population of available participants due to the nature of the school, as well as some degree of reluctance on the part of potential participants to get involved in the interview process. After the pool of potential participants was identified by the administration of the special school site in which the study was conducted,

personnel from the special school made initial contact with potential participants and obtained their tentative agreement to participate in the study. School personnel then provided me with contact information for 7 potential participants. I contacted all of the potential participants identified by the school personnel and three agreed to participate in the study. The three participants were families of students who were at various points in the continuum of transition planning for their adolescent son or daughter.

The first participant family included a mother and her daughter who graduated from this special school several years ago. For purposes of this study, this mother is referred to as “Martha” and her daughter as “Beth.” The second participant family, a mother, father and their daughter who currently attends the school are referred to as “Pam”, “Tom” and “Sarah.” The third participant family included a mother, father and twin sons, both of whom have autism; one son attends the special school. In this study, this family was referred to as “Mary Anne”, “Jim”, “Matt” and “Dan”. Consistent with confidentiality protections and best practices for qualitative research, none of these are the actual first names of the study participants. It should be noted that siblings of the young person who has a severe disability were referred to in the participant responses in each interview.

During all phases of this investigation, I adhered to the accepted protocols involving human participants. Written permission was obtained before conducting the interviews with parents. The identities of all individuals involved

in this study were protected in all phases of the study. No individual family's identity was disclosed prior to, during, or upon completion of this study.

Instrumentation

Interviews.

This investigation employed semi-structured interviews, observational field notes, and reflective field notes as sources of data. Merriam (1998) contended that the data collection instruments for a qualitative study arise from the theoretical framework and the research questions of the particular investigation. She further argued that the main purpose of an interview is to collect a certain kind of information about what an individual thinks about the subject of the interview. I determined that interviews in conjunction with observational and reflective field notes would provide me with rich data about my research questions.

Qualitative interviews have a unique conversational form that permits gathering rich data from the respondents. Kavale (1996) referred to the purpose of semi-structured interviews as a means to obtain "qualitative descriptions of the life world of the subject with respect to interpretation of their meaning" (p. 124). He further noted that, "The research interview is an interpersonal situation, a conversation between two partners about a theme of mutual interest. It is a specific form of human interaction in which knowledge evolves through a dialogue" (p.125).

In a similar manner, Yin (2009) suggested that interviews as a means of data collection for case study investigations may be thought of as guided

conversations and that interviews are one of the most important sources of case study information. Yin further contended that the job of the researcher in conducting an interview includes following their own line of established inquiry in seeking responses to established questions in a conversational manner. In this context, the researcher may ask the informant to provide his or her own insights into the questions at hand that may lead to additional questions.

My interviews were designed using a semi-structured approach based upon the guidance provided by multiple researchers. Bogdan and Biklin (2007), for example, posited that interview schedules (protocols) are intended to capture the subject's own words, allow the analysis to emerge, and should allow the researcher to collect data on unintended topics or unintended aspects of the intended topic. Semi-structured interviews, according to Barbour (2008), allow the interviewer to elicit perspectives of salience to respondents rather than the researcher dictating the direction of the encounter. Creswell (2009) recommended that an interview protocol should be comprised of a leading question and probing questions designed to elicit responses from the participants. He suggested that less structured interview formats assume that individual respondents define the world in unique ways.

Yin (2009) described the researcher's job while conducting an interview as a process that operates on two levels simultaneously. Yin offered that the researcher's challenge is to seek answers to the established questions while offering the participant opportunities for spontaneous comments.

While conducting the interviews for this investigation, I attempted to adhere to Yin's (2009) suggested method of inquiry as I conducted semi-structured in-depth interviews with the three participant families using an interview protocol (See Appendix A for the interview protocol). The interview protocol was comprised of the two research questions and additional probing questions designed to elicit further comments on each of the two central questions. I began the interview by asking each participant to "tell a story" about their son or daughter who has a severe disability. In the case of each interview, the story told by the parent led to spontaneous remarks made by each participant that addressed the focus of the first research question. The semi-structured interviews were guided by a list of questions or issues to be explored and neither the exact wording nor the order of the questions was pre-determined. The format allowed me to respond to the situation at hand, to the emerging worldview of the respondent, and to emerging ideas on each topic.

This study's interviews took place face-to-face at a location determined by each participant. Each interview was tape-recorded and then transcribed using guidelines provided by the researcher. (See Appendix C for the transcription guidelines). The tape recording was important to ensure that I was able to capture the full detail and complexity of the respondent's narrative. Kavale (1996) offered that issues of reliability in interview transcription may be addressed, in part, through improving the quality of interview transcripts through the establishment of clear procedures and purposes for the transcripts (p. 163).

Field Notes.

In addition to semi-structured interviews, I recorded observations made during the interviews with each participant and compiled these observational notes along with a descriptive narrative immediately following each interview. In addition, I composed reflective notes in a journal format following each interview. Field notes may serve as a source of data in qualitative investigations; Bogdan and Biklin (2007) identified field notes as a written description of the interview and “ideas, strategies, reflections and hunches. Field notes are the written account of what the researcher hears, sees, experiences and thinks in the course of collecting and reflecting on the data in a qualitative study” (pp. 118-119). Creswell (2009) further described observational field notes compiled during a qualitative investigation as constituting records of the reconstruction of dialogue, descriptions of the setting in which the interview took place, and the researcher’s personal feelings experienced during the interview process.

In my notes, I also observed the interactions between the participants, observed the emotional tenor of the participants, differences in participant behavior when the interview was being recorded and when the tape recorder was turned off, and the perceived level of anxiety and comfort of each participant. Throughout the interview process as reflected in my field notes, common elements that contributed to the perception of success in the transition planning process from the parents’ perspectives emerged.

Data Analysis

This study endeavored to address the issues related to what professionals need to understand about the experience of transition for students who have

severe disabilities and their families in order to provide the most effective support in planning for and accomplishing this transition. Through the process of analyzing the data obtained from the interview transcripts and field notes, responses to the research questions emerged. In case study investigations, data analysis involves a description of the setting or individuals followed by a detailed analysis of the data for themes or issues (Blomberg & Volpe, 2008; Creswell, 2009). Using a constant comparative method for analyzing the data, I was able to allow categories of response to emerge. Merriam (1998) described a constant comparative method for data analysis and Yin (2009) described explanation building as a form of data analysis appropriate for case studies. Creswell discussed assigning codes and building themes from the data and that these themes constitute the findings of the study. Further discussion of my data analysis methods follows.

Coding and Categorization of the Data.

After receiving the transcribed interviews, I reviewed each transcription by listening to the taped interviews and comparing it with the transcription. I noted any discrepancies or questions that arose. I then reviewed each tape with the transcriptionist and addressed any inconsistencies that remained. Upon completion of this step, I felt confident that the transcriptions were adequately reflective of the taped interviews and that I could undertake the process of data analysis of the interview transcripts.

Various approaches to coding data derived from interviews and observations are found in the literature. I will briefly review the approaches that

informed my approach to coding the data for this investigation. Merriam (1998) described the first level of analysis of data as “descriptive, category construction” (p.179). Merriam suggested that units of data should be sorted into groupings that have something in common and that it should be clear that categories are abstractions derived from the data, “Consolidating, reducing, and interpreting what people have said and what the researcher has seen and read –it is the process of making meaning. This meaning constitutes the findings of the study” (p. 177).

Merriam (1998) further offered that rigor in qualitative research derives from the researcher’s presence, the nature of the interaction between researcher and participants, the triangulation of data, the interpretation of perceptions, and rich, thick descriptions. The process involves the simultaneous coding of raw data and the construction of categories that capture relevant characteristics of the document’s content. According to Merriam, “Coding is nothing more than assigning some sort of shorthand designation to various aspects of your data so that you can easily retrieve specific pieces of the data” (p. 164).

Qualitative data collection and analysis are interrelated, recursive processes. Bloomberg and Volpe (2008) contended that the steps in data analysis ought to be repeated several times until the researcher feels that he/she has been sufficiently immersed in the data and that information has been derived from each data source to adequately address the research questions. In this view, case study investigations ought to present a detailed description of the case followed by analysis of the data in an attempt to discover themes. Barbour

(2008) described immersion approaches to data coding as flexible approaches that allow the researcher to work with themes emerging from the data.

Bogdan and Biklin (2007) suggested that in analyzing data derived from interview transcripts, “Certain words, phrases, patterns of behavior, subjects’ ways of thinking, and events repeat and stand out” (p. 173). These coding categories are a means of sorting the data derived from interviews with participants. Bogdan and Biklin further described coding interview data into families of codes. Creswell (2009) described organizing codes arising from data into categories. The categories of codes employed in this investigation included codes that readers would anticipate finding based on previous research, codes that were not anticipated, and codes that encompassed larger theoretical perspectives. Creswell (2009) argued that the process of data analysis involves several steps including preparation of the raw data, analysis of the data, arriving at a deeper understanding of the meaning of the data, and making interpretations of the data.

Yin (2009) described cross case synthesis as a data analysis procedure appropriate for investigations wherein multiple cases are included. As described by Yin, this data analysis technique treats each case as a separate entity and the researcher aggregates findings across the cases. Yin suggested the construction of a word table when employing cross case synthesis. Analysis of word tables leads the researcher to conclusions and cross case patterns. Yin further argued that cross case analysis relies on interpretation of data, rather than tallies of incidences or occurrences. Yin asserted that high quality analysis should attend

to all the evidence available for an investigation, address both the most significant aspects of the data as well as rival interpretations and that the researcher should employ his or her own expert knowledge of the subject at hand in the investigation.

I adapted a coding approach based on the work of Creswell (2009) and Yin (2008) and utilized the following procedures in coding the data for this study. To obtain a sense of the whole I read all the transcripts carefully and jotted notes and ideas as they came to mind in the margins of the transcripts. I then reviewed each transcript again, along with the observational and reflective field notes and listed additional observations. I noted ideas that emerged from the interview transcripts that were either supported or refuted in my descriptive and reflective notes.

During the next stage of data analysis for this investigation, I first reviewed each transcribed interview and listed derived ideas inherent in the responses of each participant. As I reviewed each transcript, categories of response began to emerge and it was evident that in both the prompted and spontaneous remarks of each participant there were similarities of response across all three participants. Each participant family's interview yielded rich and varied ideas inherent in their remarks.

I next listed the ideas derived from each interview transcript and in my observational and reflective field notes. I noted similar as well as unique ideas, and color-coded and clustered together similar topics. I organized these ideas into columns, arrayed as major topics, unique topics and leftovers.

During next step of data analysis, I categorized the ideas and assigned names to the categories. I noted the categories next to the appropriate segments of the text. In this step of the data analysis process, I utilized a system of organizing ideas into a chart with codes as headings and ideas supporting these codes as details. I utilized this chart to compile each participant's derived ideas into a composite picture of the surface content of the interview transcripts

I then reflected upon the initial categories and determined that several categories could be combined. As I settled on final labels for each category, some data were reorganized. Upon completion of this initial analysis of each transcript, I compiled a summary of the responses common to all three participants as well as those unique to any one subject. I then reviewed each list of ideas and color-coded the data for ideas in response to the each individual research question. This stage of analysis yielded five categories of response to each question with support for each category in each of the three interviews.

Analysis of the common elements in all the interview transcripts prompted me, in this stage of transcript analysis, to question the common themes and again seek support for each theme in my notes compiled after each interview. Confirmation of the data in the interview transcripts occurred through the process of cross checking the themes with my understanding and perceptions as recorded in the field notes compiled after each interview. The field notes served to assist in clarifying both the themes inherent in the interviews and the categories into which the themes fell.

My reflective field notes yielded data that contributed to the analysis of each participant's responses from a more reflective perspective than the responses of each participant alone may have indicated. I observed differing degrees of introspection and reflection evident in each of the interviewees: the first participant was quite introspective as demonstrated by both her responses and demeanor; the second participant family appeared somewhat less introspective and more focused on taking action; the third participant family displayed obvious emotion as they described their experiences.

Upon completion of this stage of data analysis, I arrived at two final categories of response to the first interview question supported by responses in each of the participants' interviews as well as my descriptive and reflective field notes. Responses to the second research question, upon analysis, fell into five categories each supported in the participant interviews as well as my field notes. I then assembled the data material belonging to each category in one place and returned to the transcripts to find the exact words that the participant had stated to support the emergent themes.

Brantlinger et al. (2005) asserted that research problems are not answered by empirical results directly, but by conclusions based on such results. Moreover, these conclusions are stated in terms of common-sense verbal language. Brantlinger further recommended that researchers using qualitative methodologies in special education research rely on triangulation, disconfirming evidence, researcher reflexivity, member checks, peer debriefing, audit trails,

thick, detailed description, and particularizeability to affirm the credibility and trustworthiness of their findings.

Validity and Reliability

Qualitative researchers must concern themselves with the soundness of their work. According to Creswell (2009) validity and reliability carry different meanings in qualitative methodology than in quantitative methodology. Creswell argued that qualitative validity implies that the researcher has checked for the accuracy of findings by using accuracy checking procedures and qualitative reliability implies that the researcher's approach is consistent. According to Creswell, one method that will help ensure reliability is checking transcripts for obvious errors; this helps ensure the accuracy of the data.

Accuracy of the data.

According to Bogdan and Biklin (2007), "In qualitative studies, researchers are concerned with the accuracy and comprehensiveness of their data" (p. 40). I assured the accuracy of the data contained in the interview transcripts through the following steps of data checking. As previously mentioned, I first reviewed each transcript with the transcriptionist and compared the tape recording with the transcript. In areas wherein questions, inconsistencies or inaccuracies arose, the transcriptionist again reviewed the tape and the transcriptionist made necessary corrections to the transcription. Because member checking assures accuracy of data analysis, I then supplied each of the participants with a copy of the interview transcript and offered the participant the opportunity, via a telephone conversation, to ask questions and make clarifications regarding the accuracy of

the transcript. All three participants approved of the accuracy of their transcribed interview.

Triangulation assures accuracy of data interpretation in qualitative studies. I checked the data and ideas derived from each interview transcript against the ideas in both my observational and reflective field notes. During the data analysis, I maintained a questioning attitude as I arrived at categories for the data. Throughout the process of data analysis, I looked for evidence that refuted the emerging hypotheses regarding the research questions and noted ideas that were unique to any one participant.

As I began to see that themes were arising from the data, I developed working hypotheses related to the research questions. These hypotheses included, first, the thinking that changes related to employment and residential status affected the parents' perception of successful transition planning. Second, how families experienced having a child who has a severe disability influenced their desires for initiating changes. Third, having a child who has a disability impacts the siblings in the family and may influence transition planning. Fourth, each family perceived themselves as unique and I wondered if this fact influenced planning for the transition of their son or daughter.

Researcher Bias.

A potential concern associated with qualitative research is how the process might be influenced by the researcher's biases. Merriam (1998) posited that because the researcher is responsive to the context; he or she can adapt techniques to the circumstances; the total context can be considered; and what is

known about the situation can be expanded through sensitivity to nonverbal aspects (pp. 6-7).

Silverstein and Auerbach (2003) advised researchers to acknowledge their subjectivity and values, and reflect on them in a systematic and disciplined way. The authors further argued that qualitative researchers believe that their own subjective experience can be a source of knowledge about the phenomenon they are studying. Examining the way one's own subjectivity influences one's research is called reflexivity, and is a goal of qualitative research. Silverstein and Auerbach stated the following:

Traditional research assumes that subjectivity and values are sources of bias that can and must be eliminated or controlled. Because qualitative research incorporates these elements, traditional researchers might assume that qualitative research is necessarily biased and therefore unscientific. Qualitative research views the issues differently (pp. 505-506).

In analyzing the data for this investigation, I was aware of my own biases regarding the subject. My views arose in part influenced from my personal experience with the subject of this investigation. First, my family system includes a daughter who has a disability and I recalled my experiences with her as she completed high school as I spoke with the participants in this study. Accordingly, in my experience, the dynamics of the family are disrupted in the process of transition from high school to the adult world. Third, I believe that independence must be balanced with caution for adults who have severe disabilities. Fourth, I believe that the family home may not be the most appropriate residence for an

adult who has a severe disability and that a greater quality of life may be achieved both for the individual and the family with an appropriate residential arrangement. Fifth, I believe that adults who have severe disabilities ought to engage in some sort of work. Finally, it is my experience that the educational system does not always turn mandated practices into reality

Chapter 4

Findings

The purpose for this study was to investigate factors identified by parents as contributing to successful transition planning for students who have severe disabilities. Two research questions guided this study. First, from the perspective of parents of students who have severe disabilities, what factors contributed to a successful transition from secondary education services to postsecondary adult services? This question addressed the observable changes in residence, employment, and social interactions that take place during the transition from adolescence to adulthood for persons who have severe disabilities.

The second question investigated in this study was what factors influenced parental perception of family well-being during the transition planning process? As stated previously, family well-being, in the context of this study, was defined as an aggregate of positive and negative indicators of individual, dyadic, and family adjustment (Blacher, 2001). The second question arose from research, cited earlier in this study, which indicated that successful program outcomes during transition did not necessarily translate into successful outcomes for family life and that enhanced quality of life is a valid measure of the effectiveness of services provided for individuals who have severe disabilities.

A special school for students who have severe disabilities served as the setting for this multiple case study investigation. The data for this study, collected during October 2010, were derived in close proximity from interviews with three families of present and former students at this school. Additional data were

derived from the researcher's observational and reflective field notes. As described in Chapter 3, analysis of the data derived from the semi-structured interviews, as well my field notes, yielded the findings that will now be discussed. I will first present findings from each of the three individual cases. Themes common to all three cases will then be identified in relationship to common elements that emerged in all three of the families' responses to the questions.

Cases

Martha

The first participant family in this investigation was comprised of a mother and her daughter who graduated from the special school several years ago. For purposes of this study, this mother was referred to as "Martha" and her daughter as "Beth." I conducted the interview with Martha at a public site of her choosing. Martha had much more to say in response to the second interview question than she did in response to the first question. In the initial analysis of Martha's interview transcripts, 19 ideas emerged from her responses to the research questions as well as her spontaneous comments. In the initial stages of data analysis, 6 of these ideas were coded in response to the first research question and 13 of the ideas were coded in response to the second research question.

In response to the first question, what factors contributed to the perception that transition was successfully being planned for, Martha's remarks yielded the following ideas recorded here in the participant's words with minimal editing for clarification or explanation.

- I wasn't sure what to expect because she was my first child and I didn't recognize the disability right away because I had nothing to compare her to.
- She was six months old before we had a diagnosis of a chromosomal anomaly, autistic tendencies and behaviors, and a small heart.
- Parents recognize the need for repetition for their kids to learn a skill. (i.e., skills for living independently).
- Being accepted by the community is more important to parents than academic or vocational learning.
- Parents worry that their kids won't have any friends (after leaving high school).
- Parents struggle with the philosophical concepts of inclusion.
- No cookie-cutter way to educate students who have developmental disabilities just like there is no cookie-cutter way to educate other kids.
- Parents' perceptions of what works in school are influenced by the experiences of other parents.
- Gaining independence in getting around (is crucial).
- Physical impediments to independence as an adult (incontinence, etc.) need to be planned for.
- The fact that the young adult child likes going home to the parents' home and also likes returning to the outside of the home living situation is an indication to the parent that the transition to the living situation is successful.

- Working at a work situation while still in school seemed to make the transition go well.
- Parents' perspectives were at first that when she graduates she ought to get to go into a totally different situation like all other kids. Realized this would be to fulfill their ideas about what ought to happen and not what would be in my child's best interests.
- Graduation is marker in a process that is already in place.

In response to the second research question, Martha's remarks yielded the following ideas:

- Having a child with a disability is an adjustment process for the family (during the process of transition).
- The relationship between the parents changes/adjusts/must be adapted to encompass the responsibility as the partners parent a child with a disability.
- Having a child who has a disability may influence whether or not the couple chooses to have other children and/or the timing of having siblings.
- A relationship with the child who has a disability is important to the sibling(s) of the child.
- Having a child who has a disability influences the family dynamic positively (she helped me raise my other two kids with a sweet spirit).

My observational field notes included remarks about Martha's emotional reaction to her friend who stopped to visit with Martha while the interview was being conducted. In addition, my observational field notes contained information

about Martha's emotional tenor during the interview. Martha mentioned her two other children frequently throughout the interview, as, it will be noted later, did the other two participant families.

Pam and Tom

The second participant family, a mother, father and their daughter who currently attends the school are referred to as "Pam", "Tom" and "Sarah." This interview took place in the family's home; Pam was present when the researcher arrived and Tom arrived shortly after the interview began. The initial analysis of data derived from the interview transcripts yielded 11 ideas inherent in the responses of these participants. In contrast to the first participant family, in the initial analysis of the data, the preponderance of ideas coded to the first interview question was far greater than the second. Eight ideas were coded to the first research question and 3 ideas were coded to the second research question.

In response to the first research question, this participant family's interview yielded the following ideas:

- She was born with Cri Du Chat syndrome. She was diagnosed at about a month old. She had the cat-like cry that is one of the main characteristics of Cri Du Chat.
- There are 30-50 children born with it each year in the United States.
- So probably our biggest challenges have been finding information.
- We've gone to Iowa City and they are more going "Oh, can we study her?" type of thing.
- Training in vocational tasks may have payoffs in other areas (like at home).

- Safe environment at school (will be replaced with a different environment).
- Family decision to wait until after public school is completed to place their daughter in a group home.
- Family decision to begin to use available services like respite care in order to have some time to spend with siblings.
- Social interactions with friends take on a different appearance with students who have disabilities (just being in the same location as other students is being with her friends not necessarily a lot of interaction).
- No comprehension of money; they are teaching her about shopping and using money at school.
- Everyone likes to be able to do tasks that they feel good about accomplishing.
- She does not independently travel around the city (must be planned for).

Ideas generated in responses to the second question were as follows:

- You get a different perspective on what you appreciate in life.
- School staff works with the philosophy that the family will know it's the right time to make transitional changes when they know it. There is no trying to tell the family when the right time is. The right time will change in your mind.
- The brother is very good with Sarah.

My observational field notes regarding this interview yielded information about the interactions between Pam and Tom and their involvement in a national support group for families who have children afflicted with the same syndrome as

their daughter. My observational notes also included information about comments related to the effects having a child who has a disability has on the other children in the family. The most striking comments in my field notes were regarding Tom's emotional tenor during the interview. He appeared close to tears several times as he spoke about his daughter. His devotion to his family was palpable as was his desire to provide for the best future possible for Sarah.

Mary Anne and Jim

The third participant family was comprised of a mother, father and twin sons, both of whom have autism; one son attends the special school. In this study, this family is referred to as "Mary Anne", "Jim", "Matt" and "Dan". The interview took place in the family's home. The couple's daughter was also present during the interview. The initial analysis of interview transcript data yielded 12 ideas in the responses of these participants. Nine of these ideas were coded to the first research question and 3 of the ideas were coded as responses to the second research question.

Ideas in response to the first research question were as follows:

- They were born at 23 weeks 5 days in Iowa City. They weighed 1 ½ lbs and they were 12" and 12 ½" long.
- They gave them less than 10% chance of making it because they were boys.
- Unique challenges with twins; double unique challenges with twins who have medical concerns (in planning for transition).

- Not too many friends in school, not friends who come over and spend the night.
- Accommodations being made in the high school curriculum and environment for him.
- Dealing with the issue of him starting to think about what he wants to do after high school and not being able to do some things (like be a firefighter) like his dad because of his disabilities.
- Helped that there is another medical condition (seizures) that will prevent him from driving.
- Also helped that medical personnel were able to talk with him about his condition.
- Parents working with him on work related social skills (you can't yell at the boss).
- Mother is beginning to think about future living arrangements for her boys outside their family home; struggling with what would their family do if something happened to them (the parents) who would care for the kids.
- Even parents who are aware and on top of things need guidance in negotiating the transition process: we wouldn't have thought about guardianship for the boys if it wasn't for the staff at the school.

In response to the second research question, this participant family offered the following:

- They look like two perfectly normal boys until you start talking with them.
- The boys are very close to each other.

- Every decision we make about their future is emotionally charged and scary.
- Hannah has given up a lot already.

My descriptive field notes about this interview included observations about the affectionate nature of the couple's interactions with each other. Both Jim and Mary Anne told stories about their sons' athletic accomplishments and their relationships with their sister. The family spoke at length about their extended families and how fortunate they felt to be living in a small town.

Cross Case Analysis

Research Question #1: Successful Transition Planning Themes

After conducting the initial data analysis for each case, I synthesized and categorized the data from all three cases. Upon completion of the data analysis of the three participants' responses to the first interview question, data fell into two final categories. The first category of responses was coded as "uniqueness of experience" This categorization was derived from responses that acknowledged that the perceptions of the challenges and uniqueness of their experiences as parents of a child who has a severe disability played a role in the perceived success of the transition planning process.

A second category of ideas was derived from responses that parental perceptions of a successful transition experience were enhanced if transitional changes in either residential status or employment were initiated according to a timeline established by the family. This category of response was coded as "initiation of changes." Specifically, parental perceptions that transition planning

was successful were enhanced if either residential changes or employment changes were undertaken while the student was still attending school. This category of response was coded as “implementation of changes”. With subsequent data analysis, I determined that these two categories could be combined into one final category labeled “initiation and implementation of changes”. Further discussion of these thematic categories of response, along with supporting evidence from the transcribed interviews and researcher’s field notes, follows.

Uniqueness of Experience

The “uniqueness of experience” categorical theme of responses to the first interview question arose from the belief, held by each family, in the uniqueness of their experiences of parenting a youngster who has a severe disability. The discussion of the impact of having a child with a disability spontaneously arose as each interview began. This commonality may be pertinent to understanding the responses of the participants in addressing the research questions. The youngster, who was the focus of the interview with each family, suffered from a relatively uncommon or challenging medical condition. The perception that parenting their child presented extraordinary challenges arose in each interview. All three participants indicated that their child’s condition affected their perceptions of themselves as parents and had influenced family dynamics and decisions, including decisions about transition. Acknowledgement of the family’s perceived uniqueness arose as a factor contributing to their perception that the transition planning process was being successfully carried out.

Excerpts from each interview illustrated this point. The participants' words were recorded verbatim and are included here as they appear in the interview transcripts. The first participant parent, Martha, spoke about her 22-year-old daughter, Beth, who has a relatively rare chromosomal anomaly. In speaking of her daughter, Martha related the following:

When we got Beth's diagnosis from the doctors in Iowa City the genetic testing doctors when it was determined that we weren't carriers of anything that it just was a fluke and we were lucky enough that she weathered it and her chromosome actually she's considered a one of a kind which indicates to them that there probably are a lot of other people that have this chromosomal arrangement and it's just not that unique and I didn't realize there could be more than one situation going on at a time. (Personal communication, October 4, 2010).

Pam and Tom, parents of the second participant family, are raising a daughter who has Cri Du Chat syndrome. They spoke of their daughter's condition as follows:

She was born with Cri Du Chat syndrome. She was diagnosed at about a month old. She had the cat-like cry which is one of the main characteristics of Cri Du Chat. With her syndrome there are 30-50 children a year in the United States born with it so probably our biggest challenges have been finding information (Personal communication October 15, 2010).

The third participant family consists of Mary Anne and Jim who are the parents of twin boys, Matt and Dan. The boys were born prematurely. Both Matt and Dan have autism. Dan attends the special school that was the site for this study. Jim spoke about his sons with the following words:

They were born at 23 weeks 5 days in Iowa City. They weighed 1 ½ lbs and they were 12" and 12 ½" long. They gave them less than 10% chance of making it because they were boys. Girls are a little stronger than boys when they are that small. We got teachers, the autism board and everything that (unintelligible) and that's the only thing we could figure out. It had to be autism. They were as shocked as we were (Personal communication October 16, 2010.)

Initiation and implementation of changes.

The second category of responses identified in the interviews as contributing to a successful transition experience involved the initiation and implementation of changes in the residential and employment situation for the student. Three factors arose in both the theme of change in residence and employment. First, parents preferred that the implementation of changes in residence or employment be undertaken incrementally according to a timetable guided by the family's identified and expressed needs and plans. These needs and plans fluctuated throughout the transition process. Second, families preferred that changes in residence and changes in employment not occur simultaneously. Third, families may prefer that changes in residence and/or employment occur while the student is still attending school and in a more stable

environment. Each parent's experience related to changes in residential status, employment or both contributed to the understanding of the impact these changes have on the perception of a successful transition.

As described in her interview, Martha indicated that the move for her daughter to a group home occurred as part of a more comprehensive family restructuring. Martha recounted, "It was the routine and the structure that was going to be most important for her was when we started investigating group home opportunities (Personal communication, October 4, 2010). Related to the timing of changes for their daughter, Pam and Tom stated:

You know a lot of people told us to do something before she leaves school and we're kind of we think I mean we've been married long enough we think we never really had a total discussion of it but we kind of came to the conclusion we're going to wait until after (special school) to put her in a group home. It's not like we sat down and talked about it. It's kind of the closer it gets now it's like we're not ready but she'll go to (special school) until she's 21 and then we definitely plan on having her go into some type of assisted living I mean group home (Personal communication October 15, 2010).

Mary Anne and Jim described the process they were undergoing as they contemplated changes for their sons with the following:

We are about that and at first we were like we don't want to do it. We want them to stay with us and have them each go get a job and then go to their job and come back. But then we got thinking too they said you know

you got to remember like let's say something would happen to you and Jim you don't want to throw them in a group home right away. You want to put them in one and then be able to go with them go get them and come back and do things with them gradually so they will be ok with it (unintelligible) just like throw them in there and just have them to deal with it with nobody there to help them. I still want to keep them home. But I think eventually when we get a little bit older we probably will do some kind of group home thing maybe or do like get them both in an apartment together and have people come and stay with them and do things with them (Personal communication, October 16, 2010).

Research Question #2: Family Well-Being Themes.

Responses to the second interview question, "What factors influenced parental perception of family well-being during the transition planning process?" fell into four categorical themes related to parental perceptions of family well-being during the transition planning process. I identified the following 4 themes within the participants' responses.

- Sensitivity expressed by professionals to the emotional impact of parenting a child who has a severe disability, especially the continuous adjustment process experienced by parents of a child who has a severe disability
- The importance of social development for a child who has a severe disability

- The impact of the presence of a child who has a severe disability on siblings; and
- The acknowledgement by professionals that the family's needs and preferences will fluctuate during the transition planning process.

These four categories were coded with the following labels: Professional Sensitivity, Social Development, Sibling Impact, and Fluctuating Family Needs.

Of the factors identified by Blacher (2001) as comprising family well-being during the transition planning process, evidence of two (negative and positive impact of the transition process on family well-being and the adjustment of caregiver burden during the period of transition) were mentioned in some way by all three participants.

Professional sensitivity.

All three families mentioned the importance of sensitivity on the part of the professionals to the emotional impact of parenting a child who has a severe disability as a factor that contributed to their perception of family well being during the planning process. Acknowledgement that parenting a child who has a severe disability is experienced as a continuous adjustment process for the family was mentioned as a means of expressing that sensitivity on the part of the professionals involved with the family. During the transition planning process, individual parents, the couple and the family as a whole experienced varying emotional reactions to changes associated with transition. This on-going adjustment necessarily impacted the parents' perception of the well being of the family.

These points were evident in the words of the participant families. For example, Martha described the adjustment process associated with her daughter Beth.

She is my first my first child and we didn't have any indication when I was pregnant that there would be complications. So the fact that she was developmentally delayed didn't probably have as much of an impact on me as it would other mothers that have other children to compare the progress or lack of it with (Personal communication, October 4, 2010).

Similarly, Pam and Tom described the adjustment they experienced in anticipation of their daughter's need for a guardian as follows:

They've had an attorney talk to us you know probably the hardest thing for me is going to court and saying that you know my child will never be able to make decisions. I think the biggest thing we've come to is we know Sarah better than anybody and when the time is right we'll know it (Personal communication, October 15, 2010).

Mary and Jim also expressed their adjustment to the challenges associated with parenting their sons with these words:

They tell us that we are very fortunate that they both did make it. Usually one or the other will live and usually, as we said with the boys being so small, usually they don't make it but we got very fortunate and they both survived. We were there for like five months in (unintelligible). By the time they came home they were more like 7 lbs something after that amount of time. Andrew came home first and then Austin got sick so he

had to stay for another month. But it was kind of nice because then we could deal with the one first since we hadn't had any kids yet. We didn't have to deal with both of them right away. We got used to the one for a month and then we had the other one come home so it wasn't two at once. It was hard leaving the one down there. I cried all the way from (unintelligible) all the way home (Personal communication, October 16, 2010).

Social Development.

The student's social development evidenced as "having friends" was mentioned in the participants' discussion of their child's educational history and comprises the second category of responses. In fact, for the participants, social development and having interpersonal relationships during the transition process was perceived as more important than any academic or vocational learning that occurs in the school setting. It might be inferred that the family's wishes for the child who has a disability to have companionship from others outside the family not only to somewhat normalize the social life for the child, but to provide a means of interactions for the child to alleviate the sole burden of this from the family. Each participant family's perspective on the importance of social relationships is illustrated with their remarks. Martha stated the following:

I will back-up just a little bit because I think it plays (unintelligible) my focus for her. Beth when after we realized her diagnosis I'll be honest the thing that was hardest for me to accept or the point of her disability that kept me

up at night was the fact (unintelligible) a mom that she might not have friends. That was just (unintelligible) I mean I still get choked up when I think about anybody not having those kinds of relationships but especially her. I just worry. That's my concern always. What kind of an environment, what kind of a setting will be the best for her in order to establish some friendships or some healthy relationships? (Personal communication, October 4, 2010).

Pam and Tom expressed similar concerns for their daughter Sarah. "If would've went into a classroom she would've had one on one which she would've loved and she probably would've just pretty much coexisted or existed with the aide you know" (Personal communication, October 15, 2010):

Mary Anne and Jim discussed social relationships with respect to their son Dan with these words:

He does really good with that but a lot of kids obviously don't want to be social with him at school because he's got disabilities. That first year we had little problems with him his freshman year where people were picking on him, calling him names and stuff. We had to go to school and get that all taken care of because it was really hurting his feelings and stuff. He doesn't really have too many friends in school and he doesn't really have friends that come over and spend the night. But like he will like...like if he goes with a group of people he'll always go to like the 8, 9, or 10 year olds and play with them. He likes to be with that group of kids (Personal communication, October 16, 2010).

Sibling Impact.

The third thematic category of response to the second interview question was the impact on the life of siblings of the presence of a child who has a severe disability. Relationships with siblings were affected throughout the process of planning for and carrying out the transition from public education to adult services. Martha discussed the impact having a sibling who has a severe disability has had on her other children:

But as far as having another child close to Beth's age and luckily it was a girl they shared a bedroom. In fact they slept together (unintelligible) queen-sized bed because Beth could not or would not sleep alone. So she was either sleeping in her parent's bed or wandering around. We couldn't have that either. So Amy would sleep Amy slept and they slept together in the same bed for well until Beth went to the group home (Personal communication, October 4, 2010).

Pam and Tom described the impact raising a child who has a severe disability had had on their other two children:

We have a son who is 21 who does not live here in town and we have a 15-year old daughter. I think because of her delay her social delay she seems more like a younger child now because (her sister) has passed her as far as her development with friends and she's driving and all that (Personal communication, October 15, 2010).

Mary Anne and Jim described how their daughter relates to their twin sons:

That's the funniest thing with our daughter. When we're gone she's mother hen with those guys (unintelligible) babysitting. But as soon as we walk in that door she's hitting them, picking on them. She goes from mother to sister in like two seconds. It's just funny though how it's like she turns around. We can't plan on her to give up her life to stay home to stay with the boys. She has already given up a lot (Personal communication, October 16, 2010).

Fluctuating Family Needs.

The fourth category of response involved the process of planning for transition as it was experienced by each family. Transition planning is a fluid experience that does not necessarily follow a linear path. As such, the planning process must necessarily be guided by the family's understanding of where they are in the process of guiding their son or daughter into adulthood and the type and level of support they seek in that process. Martha discussed her experiences with her daughter, Beth, with these words:

As we got familiar we started talking about her options because even though she lives in the group home the work site was an option but there were other options and the (special school) staff especially was excellent at sharing with us other opportunities so we didn't feel pigeon-holed. But about three years out we started talking about options when she was maybe 15. But when she was about 18 or so and we were thinking seriously about it my first thought was if she's going to graduate she should be able to progress into something all together different like other

kids get to do and for other kids or regular kids (unintelligible). But I came full circle and realized for Beth that would be very traumatic if I completely (unintelligible) from her situation and I was able to talk her (unintelligible). So we came full circle and realized that that wasn't the best thing for her and it may not have been the best thing for (unintelligible) but we were just kind of we were just for a brief amount of time kind of like (unintelligible) kind of overlooked the fact she was a child with a disability or a young adult with a disability and were considering a whole new life for her and that would have been disastrous (unintelligible) for her (Personal communication, October 4, 2010).

Pam and Tom expressed similar sentiments regarding their daughter as follows:

Well and I think you know as far as you know with (special school) I think in your study anything you can do to help the services that help the parents and I think one of the neatest things they do is the teachers will sit down and talk to you and they all say you know it's gonna be the right time you'll know it don't let anybody tell you when the right time is. The right time will change in your mind (Personal communication, October 15, 2010).

Mary Anne and Jim described their thought processes in contemplating a change in residential status for their son as follows:

So far, we are happy. We pretty much think we've got everything under control. We just got to decide what we want to do and that's

a very hard thing to decide. I mean not just for one kid, we have two to decide what we're going to do with them. And they're obviously going to be going different ways with jobs because one is going to be starting before the other one because Matt is going to be graduating first. So we'll have to decide. We've had the first meeting on it so you know it's not going to be long and the boys are going to be 21. What was it, a year and a half ago or so we started going to some meetings and stuff like that just to get the ball rolling. Because you know once they turn 18 we're no longer Mom and Dad. We're guardians so we've got that paperwork going. And they've got (unintelligible) contacted the lawyer and all this kind of stuff. We've got that, which I wouldn't even have thought about unless they had this meeting. Because you know we figured we would always be there to help them out. (unintelligible) you have to get things legal. So we started that process, too. Mary Anne and I were just talking the other night that it just scares the crap out of us for what we're going to do, the plans that we make now for the boys' future is unbelievable. I mean if we make the wrong decisions or anything like that this could really hurt the total livelihood for the rest of their lives because obviously we're not going to be around forever. We can't plan on their sister to give up her life to stay home to stay with the boys. She has already given up a lot. A few nights when we have things going on that she has

to watch the boys and stuff like that. We were fortunate enough that the people at (special school) understand what it's like. Like we we're just discussing a little while ago, it's not like you're sending the kid once he graduates sending him to college and they're gone see you at the end of the semester (Personal communication, October 16, 2010).

Interpretations

Both of the questions asked in the interviews prompted more comments and spontaneous dialogue I had anticipated. I did not need to ask the probing questions I had prepared. Each family appeared eager to tell the story of their family's experiences. All three related stories about their children to illustrate their responses. My field notes reflected that the two married couples appeared loving and affectionate with each other during the interview process.

Common concerns, as described in the responses to each of the questions, connected the participants' experiences. While responses from each of the families yielded similar content, each of the participants presented a unique perspective in response to the interview question. The first participant family, Martha, is further along in the process of transitioning her daughter to adult services. I speculated that her deeper understanding of the elements that contributed to her family's well being may be the product of time to reflect upon the experiences. The other two participant families were at similar points in the planning process. Both of these families were more deeply involved in the current planning of residential and vocational services for their children. I would

speculate their lengthier responses to the first interview question, therefore, made sense.

In the direct responses to the interview questions as well as the spontaneous comments themes arose that connected the two research questions and provided the most salient finding of this investigation. That is, the well-being of the family appeared to be the overriding factor in determining the parents' perception that transition was successfully being planned and carried out. If the parents perceived that the family would be "all right," during this challenging time, the transition planning experience was deemed successful. I would offer that in the limited context of this investigation, family well-being may serve as an indication of a successful transition from services provided through the K-12 educational system to services provided through the adult service system. My field notes confirmed the hypothesis that families' perceptions of their overall well-being served as the best indicator of successful planning and implementation of the transition process. In other words, for parents, satisfaction with their own level of participation in the process may be viewed as an appropriate indicator of a successful transition.

Chapter 5 will further explain the findings of this study in relationship to recommendations for special educators' practices in planning for transition for students who have severe disabilities.

Chapter 5

Summary, Conclusions, Discussion, and Recommendations

This investigation examined factors related to successful transition planning for students who have severe disabilities. Two research questions guided this study. First, from the perspective of parents, what factors contributed to a successful transition from secondary education services to adult services for a student who has a severe disability? Second, what factors influenced the parents' perception of family well-being during the transition planning process? A special school for students who have severe disabilities served as the setting for this multiple case study investigation. The primary data for this study, collected during October 2010, were derived from interviews with parents of both present and former students who attended this school. Additional data were derived from the researcher's descriptive and reflective field notes.

Limitations

The limitations of this study included the limited pool of participants due in part to the nature of the special school chosen as the site. Because of the nature of the special school, the conclusions drawn from this study may not be transferable to a larger population. All participants were of the same ethnic group and similar socioeconomic status. The multiple case study design, consisting of three participants, offered a small sample from which to draw conclusions. The participants who agreed to participate in the study may have been predisposed to comment favorably on the philosophical aspects of education for students who have severe disabilities as well as their experiences.

Conclusions

The findings of this study that emerged through the process of data analysis indicated that the experiences of parents of students who have severe disabilities have common elements. In each case, the interview process yielded more comments and spontaneous dialogue than I anticipated. In these spontaneous comments, supported through my field notes, I discovered that all three families used their own sense of well being as an indication of the success of transition planning for their son or daughter. More specifically, family well-being appeared to be the overriding factor in the perception that transition planning was successful. This study, then, appeared to support the findings of previous studies which indicated factors contributing to a sense of perceived overall family well-being may be an appropriate indication of a successful transition experience. (Blacher (2001); Brown, Schalock, & Brown (2009); Kim & Turnbull (2004); Neece, Kraemer, & Blacher (2009).

The participants' responses to the research questions fell into two broad areas: first, responses that could be characterized as surface level or operational level responses that lend themselves to recommendations for transition planning practices related to the timing and nature of planning for changes in residence or employment as part of the transition planning experience. These themes arose primarily in response to the first research question, but were embedded in responses to the second question as well. The second category of response involved the participants' experiences of the perspective taken by the professionals in the transition planning process and their ability to understand,

empathize and guide the parent and the youngster through the process of transitioning for adolescence to young adulthood. These comments arose in response to both the first and the second question and were embedded throughout the interviews with each participant.

Several themes evidenced themselves as I analyzed the data. The first theme may be understood as a commonality of experience related to parenting a youngster who has a severe developmental disability. The second and third themes identified in the interviews as contributing to a successful transition experience involved the initiation and implementation of changes in the residential and /or employment situation for the student. Three factors appeared commonly in both the theme of change in residence and employment. First, undertake changes in residence or employment according to the family's timetable. Second, avoid making a change in residence and employment simultaneously. Third, make every effort to initiate changes in residence and employment while the student is still enrolled in school as school provides a stable environment.

Recommendations

Educational Recommendations

The data derived from this study and the conclusions drawn from that data lead me to make the following four recommendations for special education professionals involved in planning for and implementing transition planning for students who have severe disabilities. First, as families undertake planning for transition, assist them in understanding that transition is a process involving the

entire family. This understanding may be enhanced by training educators to understand how families adjust to parenting a child who has a severe disability throughout the lifespan of that child.

Second, plan for changes in residence and or employment for the student in accordance with the family's expressed needs and wishes. Educators may more fully understand the family's needs and wishes through conversations arising through thoughtful use of transition assessments. Do not allow "the way we usually do things" to guide this process. Instead, approach each case with an open mind and a willingness to work in partnership with the family,

Third, acknowledge that the family may view their experience as unique from that of other families – even families who have students with the same or similar disabilities. Approach the transition planning process with sensitivity to the family's perceptions that they view themselves as isolated. Professionals may be wise to provide families with opportunities to connect with other families who have a child with the same or similar needs in order for them to see that others have similar experiences and to have a model or partner in negotiating the transition process. Feeling unique and isolated contributes to the family's perception that their experience is so unique that no one could possibly understand or provide support and may increase feelings of mistrust of both the educational and adult service systems.

Fourth, seek ways to enable students who have severe disabilities to participate in the transition planning process. Martin et al. (2005) examined the match between the vocational choices made by young adults who have severe

disabilities and the choices caregivers made on their behalf. The results of this study indicated that the choices made by individuals differed from those made by caregivers on their behalf.

This current investigation may lead educators to attend to the recommendations made by Martin et al. (2005) and may provide particularly relevant information for professionals as they participate in the process of transition planning and assessment for students who have severe disabilities. Given an accessible method for making choices for their youngsters, the authors suggested that parents would have utilized this information as a key part of the transition planning process. A means for effectively communicating with persons who have severe disabilities plays a crucial role in their ability to act in ways congruent with self-determined behavior.

Recommendations for Future Research

Further investigations into transition planning for students who have severe disabilities may first arise from the limitations of this study. Given the limited pool of available participants for this study and the even smaller number of participants, additional investigations with similar populations of students would add to the available knowledge regarding transition planning for students who have severe disabilities. In addition, similar investigations with more diverse participants would further add to the knowledge base.

This study utilized semi-structured interviews with the parents of students who have severe disabilities. Enhanced methods for effectively communicating with students who have severe disabilities would permit future researchers

access to the opinions of students who have severe disabilities. Investigations wherein the students themselves could participate would provide insight into the preferences of the students themselves.

Given the communication limitations through which persons who have severe disabilities may express their choices, research is called for in response to the following three questions. How can educators best maximize the participation of students who have severe disabilities in the planning and execution of transition from public school services to adult services? What do educators need to learn and implement with respect to instruments, methods, and technologies to effect meaningful participation by students who have severe disabilities? How might educators reconcile the paradox of the responsibility of the guardians of young adults to both involve them in meaningful ways and protect them from long-term consequences of choices that would adversely affect their health and well-being?

Final Thoughts

For a young person who has a severe disability, the transition to adult life may mark the beginning of a period of enhanced independence or a period of increased limitations. For many of these young persons dependence on life-long care provided through the adult service system is a reality. The quality of support provided for adults who have severe disabilities often depends on the continued advocacy provided by the individual's family.

Policy affects practice in both the educational system and the system of adult services. Certo, Luecking, Murphy, Brown, Courey, and Belanger (2009)

proposed two national policy shifts that, according to the authors, would improve support for persons who have severe disabilities throughout their adult lives. These proposed policy shifts would allow public school systems to directly contract with service providers to facilitate the transition to adult employment and would mandate entitlement, through a revision in the Developmental Disabilities Assistance and Bill of Rights, to services for adults that mirror educational services under IDEA. The authors argued that legislative change is necessary in order to connect the systems of support in meaningful ways and to fully operationalize the transition requirements of IDEA. The authors further argued for service integration and elimination of a fixed school site for students ages 19 to 21 who have severe disabilities. Certo et al. asserted

The locus of services must shift to a total community immersion approach with students accessing preferred work and off-work activities on a full-time basis in natural functional community environments so that the actual outcome of transition is that of students fully included in their communities with direct-hire, individualized employment and with the skills and social supports in place needed to access stores, services, institutions of higher education, and recreation and leisure activities and services. Further, they should be served in their final school year by a community rehabilitation agency under subcontract with the public schools and exit school with services authorized by the state rehabilitation and developmental disabilities systems to continue support by the same agency. In short, the

day after graduation should look no different than the day before for the individual exiting the school system (p. 89).

Finally, the conclusions reached in this investigation lead me to recommend additional study regarding the needs of parents as they approach transition planning for their son or daughter who has a severe disability. Further study with a larger number of participants from varied school communities would lead to a deeper understanding of the needs of parents during this challenging period in the lives of their children.

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Appendix A

Interview Protocol

1. Tell me about _____. What are his/her likes, dislikes, strengths. What story do you always tell people who have just met your son/daughter that illustrates his/her personality?
2. Tell me about your experience with planning for your son/daughter's transition
3. What are your son/daughter's current living arrangements?
4. Is your son/daughter employed?
5. How does your son/daughter manage transportation?
6. How does your son or daughter manage money?
7. Tell me about your son/daughter's social relationships and friendships.
8. How is your family handling the transition of your son/daughter?

9. How will you know whether or not your son/daughter has made a successful transition to adult life?

10. What would you like your son/daughter's school to know about your experience of transitioning your son/daughter?

Additional Questions (to be asked if the interviewee does not volunteer this information)

When did the IEP team begin planning for transition?

What did that planning involve?

Who is involved in the planning?

Is your son/daughter involved in activities to prepare for the transition?

What is the involvement of adult service providers in transition planning?

What is going well in the planning?

What would you do differently?

Where is he/she living? How did you arrive at this situation?

How is this living situations working out?

Where is he/she working? How did this work situation come about?

What is going well about the current job? Does your son/daughter have plans for future jobs?

Who are his/her friends? What kind of activities does your son/daughter engage in with friends?

Are you satisfied with your son/daughter's social involvement?

What you most worried about when you think about this transition.

What are you not worried about?

What do you want to see happen for your son/daughter as they leave high school?

Appendix B

Informed Consent for Participation in a Research Study

The experience of transition from high school for families of students who have severe developmental disabilities

Dear _____,

You have been selected to participate in a research study conducted by Pamela Fields, Drake University Doctoral Candidate. You were selected to participate in this study because your son/daughter will complete high school this year. The purpose of this study is to learn about the experience of transition from high school for the families of students who have disabilities.

If you agree to participate in this study, you will be interviewed about your experience in planning for the transition of your son or daughter from high school. If you choose to participate, the researcher will contact you to set a date and time for the interview. The interview will be held either in your home or in a place of your choosing where you feel comfortable. The interview will take approximately one hour. The interview will be tape-recorded. After the interview, the interview tapes will be transcribed word-for-word by a transcriptionist. Fictitious names will be used in the interview notes and your confidentiality will be protected during all phases of the project. The transcriptionist will be instructed not to discuss the research project with anyone but the researcher. You will be able to review the transcribed copy of the interview with the researcher.

Your participation in this study will provide minimal, if any, benefit for you. Likewise, there is minimal risk involved for you if you choose to participate in the study. During the course of the interview there is the potential for experiencing emotional discomfort related to discussing your experiences with your son/daughter. Every effort will be made by the researcher to minimize any emotional discomfort you may experience and you may terminate the interview at any time. In addition, every effort will be made to protect your confidentiality; there is however, minimal risk involved. Your identity and any information that is obtained through this study that can be identified with you will remain confidential and will be disclosed only with your permission. This research study is part of the doctoral program at Drake University and results of the study will be published in a dissertation.

If you agree to participate in this study, your signature on the line below indicates that you understand the following:

I understand the purpose of the study and agree to voluntarily participate knowing that that I may withdraw from the study at any time or choose to not have my data reported in the dissertation without penalty.

I understand that all data collected during this study will be stored securely and will be destroyed upon completion of the study.

I understand that I may choose not answer certain questions during the interview.

I understand that the interviews will be taped and transcribed and that my identity will remain confidential.

If you have any questions or concerns regarding this study or your rights as a participant in this study, please contact the principal investigator, Pamela Fields, at 563-580-3837. If you have any questions about the conduct of this study, contact the Drake Institutional Review Board (IRB) at 515-271-3472 Or by email at irb@drake.edu.

Your signature indicates that you have agreed to participate in this research study and that you understand the information contained herein.

Signature: _____ Date: _____ Telephone-

Contact Information:

Pamela Fields
2999 Deerwood Circle
Dubuque, IA 52003
(563) 580-3837

Drake University
Institutional Review Board (IRB)
(515) 271-3472
irb@drake.edu

Appendix C

Transcription Instructions

- Type in single spaced block paragraph format, double space between each speaker
- Type verbatim - meaning exactly the words that are said on the tape - including repetitions of words said by the interviewee.
- If you cannot keep up with the speaker, stop and start as needed.
- If a speaker's words are difficult to understand, listen three times. If you still don't understand, mark the place in the transcription and return to it later.
- Transcribe the interview exactly as you hear it. Transcriptions will include notations sounds on the tape including: pauses, laughing, sighs and intonations in the interviewee's voice. Please include the length of pauses, for example, short pause of one second and long pause for three seconds or more. Please put these expressions in a different font to distinguish them from the interview text.
- After you have transcribed the entire interview, listen to the tape one more time and read along with what you've written. The print should match exactly. Make corrections as necessary.
- If necessary, return to problem areas you've noted that weren't understood during the second play of the tape. If the dialogue is impossible to understand, and the answer seems to be an important fact or comment, do your best to transcribe the information.

- If unable to understand at all, put your best guess in brackets in the final copy, to show that it's your text, not the interviewee's words.

Appendix D

Date: June 15, 2010
From: Judith Allen, IRB Chair
To: Ms. Pamela Fields, Education
Re: **IRB Proposal #: 2009-10077**

Dear Lisa,

Acting in the capacity of IRB chair, I have reviewed your changes to your proposal entitled "**The Transition of Students who have Severe Developmental Disabilities to Post-High School Life: Parents' Perspectives.**" All changes have been approved.

As a reminder, a copy of the approved consent form will be stamped by the Institutional Review Board with the date of approval and forwarded to you. This will be the consent form you should use when obtaining consent from your participants. The approval period is from **6/15/2010 to 6/15/2011**.

If any changes are made to the protocol or if you plan to continue the study beyond the approval date, notify the IRB. Should you intend to continue your study beyond the approved time period, please submit an application to the IRB no later than **one month before the approval expiration date** to ensure compliance and continued data collection. Please feel free to contact me if you have any questions.



Judith L. Allen
Drake IRB Chair 2009-11